REPRODUCTIVE HEALTH INDICATORS

Recommendations for Developing Reproductive Health Indicators for the United States

Conference Series
Baltimore, Maryland
November 1 and 2, 1999

New Orleans, Louisiana
February 28 and 29, 2000

Phoenix, Arizona
May 22 and 23, 2000

REPRODUCTIVE HEALTH AND FAMILY PLANNING INDICATORS

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PREFACE

This report is the culmination of the work of numerous individuals who participated in a series of national workshops and smaller work teams who met through regular conference calls. In November 1999, the Office of Population Affairs, U.S. Department of Health and Human Services, convened a meeting in Baltimore, Maryland, to assess the need for a model set of Reproductive Health and Family Planning Indicators. The primary purpose of this effort was to consult with national experts and leaders in the field of reproductive health to identify needs and set priorities for the development of a set of model reproductive health indicators. The analysis and recommendations contained in this report reflect the expert opinion of the involved participants. This report will help set an agenda for a process to identify, develop, and ultimately implement a useful and meaningful set of model reproductive health indicators. It should serve as a blueprint for improving data collection and performance measurement—tools that are critical in furthering the goal of ensuring the availability and accessibility of quality reproductive health care for all Americans.

A series of three two-day workshops focused on the development of a national set of reproductive health and family planning indicators. These workshops provided a forum for bringing together Title X Family Planning stakeholders, private and professional reproductive health organizations, federal and state health agencies, advocacy groups, researchers, and other interested parties to discuss the subject of reproductive health indicators. Discussions included the need and use of indicators, the implications of indicators, and possible application of indicators to Title X Family Planning programs. Key leaders in the field of reproductive health, including those working in international reproductive health and family planning, were asked to assist in the workshops and participated in relevant discussions.

The primary purposes for developing a national set of reproductive health indicators are:

- To enhance reproductive health in the nation by monitoring the indicators in order to identify emerging reproductive health issues, needs, and disparities
- To identify the needs of reproductive health programs and assist in program evaluation
- To encourage consistency and promote cohesiveness in data collection across different agencies and programs
- To assess the impact of current and future policies on reproductive health and to guide and track advocacy efforts and fund allocation

The initial workshop, held on November 1 and 2, 1999, in Baltimore, Maryland, examined other related indicator initiatives. These included the experience of the Maternal and Child Health Bureau in the development of performance, outcome, and health status indicators for Title V Programs, and the relevance of these indicators to the development of similar indicators for reproductive health and family planning programs. During this first workshop, several regional family planning data projects were also reviewed. The second workshop, held on February 28 and 29, 2000, in New Orleans, Louisiana, focused on international indicator initiatives, including the Evaluation Project, an initiative funded by the U.S. Agency for International Development (USAID), which developed a handbook of family planning indicators for use in family planning

programs in developing countries. The final workshop, held on May 22 and 23, 2000, in Phoenix, Arizona, focused on government indicator and measurement initiatives, such as Healthy People 2010 and the Government Performance and Results Act (GPRA).

All of the workshops included an opportunity for discussions on cross-cutting issues in the plenary session, as well as discussions and reviews within smaller work teams that were formed around specific topic areas. At the second workshop, individuals were invited to participate in one of seven work teams based on their specific expertise or expressed interest in a particular topic area. The following seven key topic areas were identified:

1. Purpose and Scope of a National Set of Reproductive Health Indicators
2. Overall Design, Structure, and Framework
3. Scientific, Technical, and Implementation Issues
4. Program and Interagency Consistency
5. High-Need, Underserved, and Underrepresented Populations
6. Ethics and Service Quality
7. Title X Program Considerations

These groups met at the workshops and by conference call to develop individual papers providing guidance and recommendations on reproductive health indicators.

The information and recommendations contained in this report are derived from several sources. The national workshops provided participants with background information about various related efforts and provided opportunities for participants to review and discuss work in progress. The workshops were supplemented by a series of conference calls among the core work team members. The conference calls allowed for in-depth discussions of particular issues with input from the literature and work team members' experiences. Throughout the development period, the work team leaders coordinated efforts, sharing draft materials and providing feedback. This process allowed the teams to work in parallel and promoted consistency among the developing chapters.

In order to operationalize the indicators for various uses, the Purposes and Scope work team sought agreement about a credible, recognized, and shared definition of reproductive health in the United States. This proposed definition was presented at the Phoenix meeting and discussed by the larger group of workshop participants. A consensus on the definition of reproductive health, with its caveats and key concepts, is intended to help provide insight into what should be measured and is critical to selecting what indicators should be used. Several important international trends informed this work. One was the renewed desire of governments to improve the reproductive health of their populations and to understand and define reproductive health in a comprehensive fashion. These trends were evident in the 1994 International Conference on Population and Development (ICPD) in Cairo and also have been reflected in documents from other organizations.

The Design work team examined issues involved with an overall structure and design that corresponds with a broad definition of reproductive health, as well as the issues and action steps involved in the structure and design of a reproductive health indicator set. The work team

proposed a conceptual framework to guide the selection and analysis of reproductive health indicators, as well as a procedural framework for using the conceptual model and other resources to select indicators.

The Scientific, Technical, and Implementation work team was charged with looking at how to ensure the appropriate measurement and use of the indicators. To that end, the work team reviewed the basic conceptual and scientific criteria for reproductive health indicators, including the validity, reliability, and availability of data and the timeliness of data collection.

To minimize confusion among existing program indicators, the Consistency work team focused on a strategy to promote consistency in developing the definitions of reproductive health indicators.

The High-Need work team looked to ensure that a full diversity of individuals are represented among population samples for monitoring reproductive health and to consider specific indicators for diverse groups. The work team members reviewed strategies for the inclusion of populations with small aggregate numbers and of sparse populations that are broadly dispersed with a goal of suggesting general guidelines with respect to reproductive health indicators for high-need populations.

The Ethics and Service Quality work team addressed the intersection of ethics, service quality, and reproductive health indicators, reviewing the ethical principles and procedures that ground all research processes. The workgroup also addressed two related quality issues—recognition of the various system components where quality can be assessed and possible standards for selecting measures of quality of care.

The Title X work team presented a case study in which the principles and concepts presented in the other chapters are applied to the federally funded Title X Family Planning Program. The Reproductive Health Indicators project is important to the Title X Program because it will lead to the development of indicators that will provide program staff and administrators, advocates, and policy makers with important evidence of the benefits afforded by the full scope of services provided by Title X clinics. Indicators can be used for monitoring progress and planning for future changes and improvements. This information will be useful for program strategic planning and goal setting.

This report is intended to advance the concept of reproductive health indicators in order to move the United States toward the achievement of improved systems for measuring the reproductive health of all Americans. The ultimate goal is to use the information and recommendations presented in this report to begin a process for developing a model set of reproductive health indicators.

ACKNOWLEDGMENTS

This report represents the collaborative efforts of many individuals. We would like to thank all the participants at the workshops held in Baltimore, New Orleans, and Phoenix who contributed their expertise and critical advice to the development of this report.

This report would not have been possible without the contributions from the working group team leaders: Wendy Chavkin, Professor of Clinical Public Health and Stacey Reese, graduate assistant, Center for Population and Family Health, Joseph L. Mailman School of Public Health at Columbia University; Mary D. Peoples-Sheps, Independent Consultant; Jacqueline Darroch, Vice President for Research, The Alan Guttmacher Institute; Priscilla Guild, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, and Mary Rogers, Division of Reproductive Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC); Trude Bennett, Associate Professor, and Cathy Roweder, doctoral student, Department of Maternal and Child Health, University of North Carolina at Chapel Hill; David Fine, Research Director, The Center for Health Training; and Roberta Herceg-Baron, Managing Director of Programs, Family Planning Council, Inc. (Southeastern Pennsylvania). These individuals contributed generously of their time and knowledge to coordinate work team discussions and formulate the individual chapters. Their assistance is gratefully acknowledged.

The three national workshops and the production of this report were planned with the assistance of staff from the Emory University Regional Training Center, including Bill Chamberlain, Deb Risisky, and Sara Baden. Special thanks are due to Roger Rochat, Professor, Rollins School of Public Health, Emory University, for his assistance in moderating the national workshops, helping to coordinate the efforts of the work teams, and in reviewing the final report.

Several staff in the Office of Population Affairs contributed to the development of this report. Jennifer Todd and Evelyn Kappeler coordinated the overall project activities. Other staff provided assistance in coordinating work team discussions. Staff included Mary Bowers, Alicia Richmond Scott, Jeannine Nielsen, Tarsha Wilson, Barbara Cohen, Charon Flowers, Deborah Langer, Susan Moskosky, and Kathy Woodall.

Editorial review services for this report were made possible with support from the National Center for Chronic Disease Prevention and Health Promotion, CDC. The editorial review was conducted by Deborah Shuman, Palladian Partners, Inc.

INTRODUCTION

Indicators of reproductive health can serve a number of purposes: to describe the status of reproductive health in a given population; to track the processes by which reproductive health care is provided, as well as the outcomes of those processes; and to set goals for improving reproductive health. The growing interest in reproductive health on the part of patients, providers, and policy makers in recent decades has been accompanied by a burgeoning wealth of information and data sources. Most of the data available in the field today have been designed to assess specific problem conditions rather than the broader state of reproductive health among populations of individuals. Indeed, there is at present no widely accepted definition of reproductive health that can be applied uniformly in any measurement efforts.

Recognizing these limitations, the Office of Population Affairs (OPA) convened a series of invitational conferences to provide a forum for representatives from Title X Family Planning stakeholders, private and professional reproductive health organizations, federal and state health agencies, advocacy groups, and other interested parties. These representatives came together to discuss the present "state of the state" of reproductive health indicators, their implications, their need and use, and their application to Title X Family Planning programs. They were charged with developing recommendations for the use of a national set of reproductive health indicators and a strategy for their selection and implementation.

The work of the Reproductive Health Indicators Project has drawn upon the creative energy and expertise of a wide range of individuals in reviewing and responding to several key questions: How do we define reproductive health in the United States? What would constitute an effective system of indicators of reproductive health in the United States? What would be useful criteria for selecting such indicators, and how would they be applied in a program setting? To address these questions, the Task Force on Reproductive Health Indicators worked toward a number of objectives:

- To develop consensus on a definition of reproductive health
- To define the needs and uses of reproductive health indicators, bringing special attention to key problems
- To set an agenda for measuring reproductive heath in the United States
- To commission background papers to help provide expert advice and guidance on improving measures of reproductive health in the United States

This report embodies the results of that work. Its development has stemmed from the need to inject some agreement and consistency into a definition of reproductive health, to identify existing indicators that address reproductive health, and to create a system of common reproductive health indicators that crosses levels of government, from the national to the state to the local level. The members of the Task Force on Reproductive Health Indicators have strived to bring coherence to the field of reproductive health in the United States—working against the fragmentation, the segmentation, the categorizations into small and discrete areas. To that end, they worked from a broad conceptualization of reproductive health rather than a narrow view of the various components of individual programs, diseases and conditions, or populations.

This report is the result of a pioneering effort to provide a conceptual framework for producing a model set of indicators. Such indicators will allow policy makers and researchers to describe reproductive health in more comprehensive terms, to monitor outcomes for planning purposes, to set goals, to coordinate public and private efforts to accomplish those goals, and to evaluate the effectiveness of programs and activities aimed at improving the reproductive health of all Americans.

EXECUTIVE SUMMARY

CHAPTER 1: PURPOSE AND SCOPE OF A NATIONAL SET OF REPRODUCTIVE HEALTH INDICATORS

Definition of Reproductive Health

The following definition, developed at the 1994 International Conference on Population and Development, has been adopted for the purposes of the Reproductive Health Indicators Project:

> Reproductive health is a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes.

Key Concepts of Reproductive Health

The following caveats should ideally be applied to all reproductive health services in the United States:

- Reproductive health policies, programs, and services should be comprehensive, voluntary, and non-coercive; confidential and respectful of human rights; and age appropriate, culturally sensitive, and appropriate for men as well as for women.

- Reproductive health programs and services should be accessible to everyone without regard to sexual orientation, gender, age, race or ethnicity, citizenship, geographic location, primary language, education level, physical or mental disability, marital status, income, or insurance status. Reproductive health services are essential for the entire population, male and female, and not merely for those who are childbearing or sexually active.

- Reproductive health care should include the provision of information and services that address the changing concerns related to reproductive health in youth, middle age, menopause, and later life.

Reproductive health services for any population should include (but not be limited to) the following:

- **Men's and women's health**—The population should have access to the health care, screening, and preventive services necessary to ensure reproductive health throughout the life cycle.
- **Safe and healthy motherhood**—The population should have access to appropriate health care services that will enable women to have safe pregnancies and deliveries (if desired) and to provide families with the best chance of having healthy infants.
- **Reproductive tract infections and reproductive system cancers and other diseases**—Reproductive health care should include prevention, screening, and treatment of

reproductive tract infections, including HIV/AIDS and other sexually transmitted diseases, and of cancers of the breast and reproductive system.

- **Fertility regulation—**The population should be informed about and have access to their choice of the full range of safe, effective, affordable, and acceptable methods of family planning. Abortion, sterilization, and basic infertility services are also a part of fertility regulation.
- **Education and counseling—**Reproductive health care should include the provision of unbiased, accurate information and counseling on all aspects of sexuality and reproductive health. To ensure the reproductive health of the population, such information must be readily available and widely disseminated.
- **Developing new technologies—**Improving reproductive health entails encouraging the development of reproductive technologies as well as promoting access to and ensuring appropriate use of such technologies. Safeguards that ensure rigorous evaluation and approval, as well as informed consent, must be in place during all stages of the development and use of such technologies.

Purpose of Reproductive Health Indicators

- Describing the current and past health status of a given population
- Monitoring changes in health status over time
- Assisting in setting goals
- Holding agencies accountable for improving outcomes
- Providing evaluation or quality improvement and determining program effectiveness

The indicators chosen should allow agencies and service providers to do the following:

1. Measure progress in achieving the outcomes described by the caveats, key concepts, and definition of reproductive health
2. Identify emerging reproductive health issues and needs
3. Respond quickly and effectively to reproductive health disparities among population subgroups
4. Ensure that the reproductive health needs of the population are consistently met with quality services
5. Foster consistency in indicator definitions and data collection
6. Assess the effects of policy changes on reproductive health

Scope of the Indicator Set

The scope of the indicator set should be focused on reproductive health status and outcome measures, which should be positively defined whenever possible. At the same time, it is important to recognize the breadth of the many social and other factors that have an impact on reproductive health. The following areas should be included in the scope of the national indicator set:

- Population and Scale:
  — Age

CHAPTER 2: OVERALL DESIGN, STRUCTURE, AND FRAMEWORK

The development of a set of reproductive health indicators requires an overall structure and design that corresponds with the broad definition of reproductive health and the purposes and scope of the Reproductive Health Indicators Project as presented in Chapter 1. Carrying out this charge requires development of a conceptual framework to guide the selection and analysis of reproductive health indicators and a procedural framework for using the conceptual model and other resources to select indicators.

Conceptual Framework

The following five qualities of the conceptual framework are considered optimal:

1. **Relevance to the purposes and scope of reproductive health indicators—**The model should support the development of indicators that will do the following:

   - Measure progress in achieving outcomes described by the key concepts, caveats, and definition of reproductive health
   - Identify emerging reproductive health issues and needs
   - Identify disparities among population subgroups
   - Identify reproductive health needs of the population and the extent to which they are met with quality services
   - Assess the effects of policy changes on reproductive health

   The model should also conform to the proposed scope of the indicator set by emphasizing measures of reproductive health status and outcomes while reflecting the breadth of social and other factors that have an impact on reproductive health.

2. **Consistency with requirements of the Government Performance and Results Act—**The Government Performance and Results Act (GPRA) emphasizes the use of indicators for monitoring federally funded programs by focusing on inputs, processes, and outputs.

3. **Adaptability to reproductive health content or domains—**The model should be compatible with existing reproductive health indicators, such as those specified in *Healthy People 2010* and other widely recognized indicator sets in the field. At the same time, the model should provide guidance for the development of indicators that are not currently available or used.

4. **Documentation in the literature of relationships depicted in the model—**The model should be derived from solid research that confirms, rather than hypothesizes, relationships among domains and/or variables.

5. **Intuitive logic, simplicity, and understandability—**Because reproductive health indicators will be disseminated to people of many backgrounds, the model on which they are built should facilitate, not inhibit, their understanding and application.

The proposed model for the conceptual framework includes 17 domains, which are organized under five headings that represent the key aspects of reproductive health (see Figure 2–1):

1. Reproductive Health Status
   - Health and functioning
   - Disease

2. Beliefs/Behaviors
   - Health beliefs
   - Personal/couple behaviors
   - Use of appropriate health technology

3. Environment
   - Demographics
   - Social environment
   - Physical environment
   - Political environment
   - Health environment
   - Community norms, systems, and structures

4. Health Systems
   - Organization
   - Financing
   - Policies

5. Interventions
   - Inputs
   - Processes
   - Outputs

Procedural Framework

The procedural framework should ideally possess the following qualities:

- Systematic sequencing of development phases to allow for adequate attention to each type of indicator
- A primary focus on reproductive health status, with linkage to other indicators

- Use of existing indicators whenever possible
- Allowance for a core set of indicators selected from the larger set
- Consistency with other federal government activities and requirements (e.g., GPRA, *Healthy People 2010*, Maternal and Child Health Bureau Performance Measures)

The conceptual framework described above provides a basis on which to develop reproductive health indicators. The entire development process should involve three interdependent but sequential phases. Phase 1 is development of Reproductive Health Status indicators. Since these are the most essential indicators, they should be fully developed and perhaps pilot tested before the second phase begins. Phase 2 involves development within the Environment, Beliefs/Behaviors, Health Systems, and Interventions domains. Because all of these domains imply some type of action, they are henceforth called "Reproductive Health Action indicators" in this document. When development of both reproductive health status and action indicators is completed, a core set of indicators should be selected from the larger set. This will constitute Phase 3. Several steps are required to complete each of these phases.

Phase 1: Reproductive Health Status Indicators

1. Operationalize the broad definition of reproductive health.
2. Reduce the number of concepts.
3. Identify potential indicators.
4. For each concept, compare the candidate indicators according to relevant criteria.
5. Select indicators that best meet the criteria.
6. Consider new measures.
7. Complete the description of characteristics of the indicators.

Phase 2: Reproductive Health Action Indicators

1. For each reproductive health status indicator, identify contributing factors from current, scientifically sound research.
2. For each reproductive health status indicator, identify interventions used to modify the contributing factors in the Environment, Health Systems, and Beliefs/Behaviors domains.
3. Develop a concept map for each reproductive health status indicator.
4. Reduce the number of concepts to a manageable set, keeping in mind that the reproductive health indicators are intended to be used to monitor key events and conditions.
5. Identify candidate indicators for each concept.
6. Compare the candidate indicators for each concept according to specific criteria (e.g., those adapted from the World Health Organization).
7. Select indicators that best meet the criteria, using a systematic process for weighting and ranking alternatives.
8. Consider new measures in cases in which no indicator is available for a critical concept.
9. Complete the description of characteristics of each indicator.

Phase 3: Core Set of Indicators

The core set of indicators should be selected from both Reproductive Health Status and Reproductive Health Action indicators. Core indicators should be of great importance to reproductive health. They should represent key concepts in the definition from the 1994

International Conference on Population and Development in Cairo (e.g., male representation, specific types of health care, access to the full range of care components), as described in Chapter 1, and should include all critical domains in the model. Although a specific number of core indicators is not recommended, the number should be relatively small to encourage their widespread utilization.

CHAPTER 3: SCIENTIFIC, TECHNICAL, AND IMPLEMENTATION ISSUES

Scientific and Technical Issues

Measurement criteria that must be met in order for the indicators to accurately reflect the components of reproductive health, as defined in Chapter 1, include the following:

- **Validity:** In formulating the reproductive health indicators, discussion with various stakeholders and experts will be needed to ensure that the proposed indicators are valid, that is, that they accurately capture the components of reproductive health.

- **Reliability:** The measurement or calculation of an indicator must be consistent across groups, such as state, population, or program, as well as over time.

- **Data considerations:** For each indicator, a number of questions about the "what, where, and how" of identifying data sources should be asked and adequately answered:

— Types of data: What types of data are needed to measure each indicator?
— Availability of data: Are the data already available? If not, what must be done to collect or obtain them?
— Sources of data: What are the advantages and disadvantages of using different sources of data for each indicator being measured?
— Quality of data: What is the quality of the different data sources being used or considered for each indicator?
— Relevancy of data: How relevant are the data for small areas or subpopulations of interest?

Implementation Issues

Specifying, measuring, and using reproductive health indicators requires the cooperation of many different individuals, programs, and levels of government. Coordination between funders and oversight organizations can decrease duplication of data and indicators, making data collection and indicator use more efficient and increasing communication and cooperation across organizations. The way in which indicators will be used must be clarified in the early stages, and stakeholders should be involved in these decisions. Areas that will require focused consideration and resources include the following:

- **Clearance, approval, and support:** Clearance, approval, and/or support of the indicators initiative and process is needed from prospective national partners and data-gathering organizations.

- **Operationalization:** Selection of indicators should take into consideration the extent to which the various groups involved can contribute to the process, supply data, and use the resulting indicators.

- **Dissemination:** The dissemination of the indicators is an important step in the implementation process. The various options that are available include a complete national annual document that reports standard indicators for all or some entities, which could be published in print form or as a Web-based report; a national annual benchmark report documenting standard indicators that can be used by entities for comparison; and individual reports for specific programs, regions, or states.

- **Quality Improvement:** Plans for quality maintenance and improvement should be built into the implementation process from the very beginning. To that end, the organizations and individuals responsible for collecting and reporting indicators should have training in indicator measurement and reporting.

- **Assessment, Testing, and Revision:** Iterative assessment and improvement mechanisms should be built into the Reproductive Health Indicators Project to provide systematic review and discussion of published and reported indicators.

Recommendations

- Focus the national effort, at least initially, on outcome or status indicators rather than on process indicators.
- Involve a wide spectrum of experts, stakeholders, and consumers in operationalizing the concept of reproductive health into a number of potential indicators. Service providers and those who will be asked to provide data should be involved from the beginning.
- Identify and introduce different classes of indicators, such as basic measures, pilot or developmental indicators, and optional or rotating indicators.
- Allocate enough resources and time to ensure that indicators are measured in valid, accurate, and comparable ways across time, areas, and populations.
- Encourage the use of indicators as program goals rather than as justification for withholding resources.
- As much as possible, capitalize on using existing data and indicators rather than duplicating efforts.

CHAPTER 4: PROGRAM AND INTERAGENCY CONSISTENCY

It is important for reproductive health indicators to be consistent within and among programs and agencies because this provides comparable data that can be compared across programs, agencies, and geographic areas, as well as over time. Consistency can lead to improved quality of

care when comparisons can be made between service delivery sites or programs. Having consistent indicators within programs and with other agencies lends credibility to the validity of the indicators, because they are considered to be important by more than one group. Consistency can also potentially reduce the workload for those producing the indicators if they are doing so for more than one group. Finally, consistency reduces the time and effort of those developing the indicators, making the process as efficient as possible.

For each indicator set, the following information should be documented:

- Agency or organization leading the development
- Year in which indicators were finalized, how long they have been used, and whether they are still in use
- Breadth of the effort (i.e., international, national, multistate region, or state)

By using the above information, a database can be developed at the indicator level of all reproductive health indicators already defined. For each indicator, the database should include the following:

- Name
- Breakdown or subcategories of analysis (e.g., age, race and ethnicity, income level)
- Definition, including data sources for the numerators and denominators
- Lead agency
- Year finalized
- Years in use
- Still in use (yes or no)
- Breadth of effort (international, national, multistate, state)
- Target population(s)
- Portion of the conceptual model addressed
- Use(s) or proposed use(s) (e.g., billing, reporting requirement, monitoring, performance measure, needs assessment measure, provision of comparable data)

Once the indicators are decided upon from the conceptual model, steps must be taken to minimize inconsistencies. When there are multiple acceptable ways of specifying an indicator, a table should be produced that summarizes the definitions used by the breadth of the effort. Information in the cells should include the lead agency, data sources, the use or proposed use, and any notes about the geographical levels for which the indicator can be produced. If more than one agency or organization has specified the indicator, all definitions and agencies or organizations should be indicated. Once all definitions have been identified, the appropriate definition can be selected by using the following guidelines:

- Emphasize definitions that have consistently been used by multiple agencies or organizations (including using consistent data sources for the numerators and denominators) and at multiple levels (breadth).

- When consistency is not found, emphasize definitions that have been developed by projects with the greatest breadth; those that can be estimated at the smallest geographical

level; and/or those being used as reporting requirements, performance or needs assessment measures, or monitoring measures.

There may be instances in the selection of indicators when inconsistency is actually necessary. Examples include situations in which different denominators are required for different target populations; a currently used definition is inadequate or inappropriate for use in the Reproductive Health Indicators Project (e.g., an insufficient definition is currently used in the field); laws or regulations differ across geographic areas, leading to differences in reporting or definitions; and the availability of data sources varies across geographic areas. A process must therefore be developed for handling necessary inconsistencies. Although this is not an easy task, one approach would be to form an Interagency Data Workgroup made up of representatives of agencies or organizations, at least at the national level, that are developing reproductive health indicators or are involved in collecting the data needed to produce these indicators. Although not meant to be a complete list, the following agencies and organizations should be considered for inclusion in this group:

- Alan Guttmacher Institute
- Division of Reproductive Health, Centers for Disease Control and Prevention
- Family Planning Councils of America
- State family planning administrators
- Health Care Financing Administration
- Maternal and Child Health Bureau, Health Resources and Services Administration
- National Center for Health Statistics, Centers for Disease Control and Prevention
- National Committee for Quality Assurance
- National Family Planning and Reproductive Health Association
- Office of Women's Health

Recommendations

The Reproductive Health Indicators project group should review the list of proposed indicators and their definitions to determine whether they can agree on ways to produce consistent definitions across these agencies or organizations. If agreement cannot be reached, this group should move toward endorsing the need for inconsistent definitions. When the list of indicators is released, it is critical that the Interagency Data Workgroup has reviewed the list with definitions and added an explanation when they feel that inconsistent definitions need to be recommended.

CHAPTER 5: HIGH-NEED, UNDERSERVED, AND UNDERREPRESENTED POPULATIONS

A full diversity of individuals must be represented among the populations sampled for monitoring of reproductive health. Specific indicators should therefore be considered for diverse groups, even if the importance of these indicators is not evident for the entire population.

Principles

A set of principles has been agreed upon for the selection and measurement of reproductive health indicators for high-need populations:

1. **Optimal reproductive health and elimination of disparities should apply to all populations and to all individuals within those populations.** An "optimal" standard should be stressed as a positive goal.

2. **Priority must be given to disparities in health between the general population and high-need populations, and appropriate and adequate resources must be made available to eliminate those disparities.** This principle places major emphasis on the importance of resource allocation and addressing disparities in services and resources (versus differences among populations themselves).

Recommendations

Consideration of a broad range of populations will allow for variations in local monitoring and attention to timely problems that arise in national, state, or local settings. A commitment will be needed to continue searching for resources to achieve adequate coverage of all groups that warrant concern. Optimal coverage of high-need populations should be explored as fully as possible before feasibility is assessed. At that point, priorities will clearly need to be established.

The list below represents an attempt to enumerate groups that might require focused monitoring regardless of the current availability or quality of data. It is important to keep in mind that data can always be collapsed into larger categories but cannot be disaggregated without adequate attention to detail in data collection. This list is not meant to be exhaustive nor the categories mutually exclusive; classifications are not fixed and are not meant to imply any system of ranking.

Defining Populations:

- Gender (i.e., inclusive of males as well as females)
- Age
- Race and ethnicity
- Socioeconomic status and quality of life
- Immigrant status
- Disability status and morbidity
- Stigmatizing medical and behavioral risks (e.g., AIDS/HIV, sexually transmitted diseases, substance use disorders)
- Sexual orientation
- Residence (rural, urban, suburban)
- Institutionalization status (e.g., criminal justice system, institutions for physical or mental disabilities, nursing or convalescent homes)
- Abuse

- Women in hiding (due to, e.g., immigration status, abuse, or substance abuse)
- Cultural and religious minorities
- Policy-sensitive conditions (e.g., women who become ineligible for welfare due to time limits or other new regulations)
- Program eligibility (e.g., Indian Health Service, Title X)
- Environmental exposures (hazardous occupations or industries)
- Ethics (participation in research related to reproductive health)
- Genetics (concerns related to persons with genetic susceptibilities)

Other Considerations

Multiple Risks. Underserved individuals may have multiple characteristics that raise concerns for reproductive health. It may be useful to construct an index of need or to define a constellation of risks that are likely to coincide. It should be possible to do this without recreating the problems associated with the "high-risk" label.

Group Members. High-need, underserved, and underrepresented groups are heterogenous, and membership in such groups may be a transitory condition for individuals. It should therefore be determined what is the importance of individual-level data, including longitudinal linked data, versus ecological or aggregate population-level data and cross-sectional analyses. In addition, it should be determined how we can allow for fluidity in group membership and identity and what we can learn from variation within subgroups.

Local Representation. An ongoing process will be essential to obtain continuous input from representatives of groups being monitored. As social conditions, policies, and health care delivery systems evolve and change, members of designated populations should play an important role in developing data collection strategies.

CHAPTER 6: ETHICS AND SERVICE QUALITY

Ethics is the study of problems of right conduct in light of moral principles, in which the goal is to provide guidance on what to do and how to treat others. Sound ethical principles and procedures are necessary conditions for research on human subjects.

Ethics and Research

A broad set of issues should caution us against underestimating the problems inherent in addressing ethics and the development and implementation of reproductive health indicators. A first concern is with language—terms and definitions—and how they fit within our historical context. A second problem involves the sometimes uncomfortable fit between research and its oversight via IRBs. Despite the broad definition of "research" used in statute, IRBs routinely distinguish between various types of scientific endeavors relating to indicators. A third concern involves tying this issue of ethics and research too closely and simply to IRBs. Although IRBs play a central role in overseeing research or research-like activities, other governmental agencies and statutes also have jurisdiction over such projects.

Service Quality

As work continues on devising reproductive health indicators, two related quality issues should be addressed. The first is recognition of the various system components where quality can be assessed. The second involves examining possible standards for selecting measures of quality. For the former, evaluation of quality can be based on structure, process, or outcome. Examples of structural elements are the background and training of staff, agency capacity, technology and equipment, community service access, and even funding. The process component for reproductive health quality is particularly critical and centers on encounters between personnel and patients. This encompasses the complexities of each individual's views of the experience as well as documentation of procedures and short-term outputs. Finally, outcome measurement entails identifying and monitoring patients' subsequent reproductive health status. In addition to these challenges, it is clear that structure, process, and outcome evaluation can be conceptualized at the individual or aggregate levels.

Recommendations

Indicator System Development Process

- Provide a draft of the indicator project's Request for Proposal (RFP) to representatives from each workgroup. Feedback from this dissemination process should be part of OPA's development of the published RFP.
- Create an ad hoc committee to work with the contractor selected from the RFP process.
- Identify and recruit representatives from other government agencies, professional associations, and stakeholder groups with expertise in examining ethical and quality service issues to participate as committee members.
- Clarify policies for relevant OPA-funded outcome projects concerning human subjects review procedures. This may be particularly appropriate for demonstration programs that include evaluation components rather than explicit "research" endeavors.
- Begin a process (similar to NCQA's efforts) of determining the desirable attributes of reproductive health indicators.

Indicator System Implementation

- Ensure the development of a plan for addressing human subjects protection issues in the indicator system project. Incorporate relevant elements of this plan in all technical documents and presentations concerning the implementation stage.
- Oversee identification of the administrative unit(s) responsible for ensuring human subjects protection in the project.
- Examine the possibility of incorporating data elements from the indicator system as core measures in other OPA-funded research and demonstration projects, such as Service Delivery Improvement (SDI) grants and special initiatives such as male involvement. (The focus here is not on the technical usefulness of this approach, but rather on minimizing risks to and burdens on subjects concerning data collection.)

- Develop guidelines for the use and sharing of indicator system data. Plan for strategic partnerships with other programs engaged in related health and human service indicator systems.
- Include project activities to evaluate the impact of collecting reproductive health indicator data on key system elements, such as service quality for patients, partners of patients, service providers, and reproductive health service system change (e.g., policies, service mix, and reimbursements).

CHAPTER 7: CONSIDERATIONS FOR TITLE X PROGRAMS

In 1970, the US Congress passed Title X of the Public Health Service Act, creating a national family planning program. This legislation established a federal funding base for public and private nonprofit organizations to provide "educational, comprehensive medical, and social services necessary to aid individuals to determine freely the number and spacing of their children." Title X family planning services are available to all persons in the United States; priority is given to low-income individuals. In addition to this vast network of clinical service providers, the Title X Family Planning Program also mandates and provides funding for public information and education addressing family planning and population growth, training for service providers, and research related to family planning and population issues.

The Office of Population affairs (OPA) should adopt a set of performance indicators for the Title X Family Planning Program that address the multiple mandates of Title X legislation. These indicators should provide a basis for broad public education about the importance of family planning and the purpose of the national family planning program. Title X Program indicators should relate both conceptually and pragmatically to the national indicators that are selected as a result of the Reproductive Health Indicators Project.

Recommendations

- Develop a communications strategy for sharing the results of this phase and future activities of the Reproductive Health Indicators Project with Title X service providers. This strategy should provide for ongoing information sharing and feedback on the time frame and process of selecting Family Planning Program Indicators and their link to the Reproductive Health Indicators Project. This strategy should include how to handle the management of perceptions, facts, and misinformation that might result and interfere with establishing commitment and ownership of the indicators project by the Title X provider network.

- Building on the current Reproductive Health Indicators vision statement, issue a specific vision statement for the national Title X Family Planning Program. The vision should be based on the concepts and issues addressed by the Title X Applicability workgroup.

- If a Request for Proposal is issued and a contractor selected to complete work on the Reproductive Health Indicators Project, the workgroup strongly advises continued and substantive representation in the planning and implementation process from the Title X

service network, in addition to representation from other funding agencies, professional organizations, insurers, and individuals with related expertise.

- Continue work toward achieving consensus in defining comprehensive family planning care, as proposed within the spectrum of life span reproductive health services. This work is essential to the selection of program domains and specific indicators within those domains. This effort is also beneficial to defining the scope and quality of activities for which Title X resources are to be used or leveraged in partnership with other federal, state, or local funding streams.

- Further explore the concept of core and expanded indicators, not only with respect to the clinical services component of the Title X Programs (as presented in this chapter), but also with respect to the community education, provider training, and research components of the Title X legislation.

- Move forward with substantive integration of FPAR and GPRA reporting requirements and linkage of these with the *Healthy People 2010* objectives so that these measures can be included with the work on the National Reproductive Health Indicator Project.

CHAPTER 1:

PURPOSE AND SCOPE OF A NATIONAL SET OF REPRODUCTIVE HEALTH INDICATORS

Defining reproductive health is a prerequisite for tackling the task of developing a national set of reproductive health indicators. The definition chosen will help to guide the selection of indicators and may also be used to influence priorities for reproductive health policy and services. Seeking consensus from other groups and agencies for a definition of reproductive health is an essential first step toward creating an integrated system of reproductive health services in the United States.

BACKGROUND

Accompanying the increased international focus on reproductive health is a new interest in defining reproductive health within a human rights framework.[3,4] This interest is reflected in recent events such as the creation of a charter on sexual and reproductive rights by the International Planned Parenthood Federation;[5] the characterization of reproductive health as a human right by Dr. Gro Harlem Brundtland, Director-General of the World Health Organization;[6] and South Africa's inclusion of sexual and reproductive health rights in the Bill of Rights of its Constitution.[7] Although U.S. activists and advocates often focus on reproductive rights, they have been less likely thus far to place such rights within a broader human rights framework in the United States.

International and domestic interest in health indicators has also grown recently.[8] Indicators are seen as an essential tool for improving the reproductive health of populations and for assessing the quality of reproductive health services. The Office of Disease Prevention and Health Promotion's *Healthy People 2010*,[9] a national health promotion and disease prevention initiative, includes a list of 10 leading health indicators, one of which is responsible sexual behavior. Five of the 28 Focus Areas identified in *Healthy People 2010* touch on various components of reproductive health.[9] Although *Healthy People 2010* addresses reproductive health, the creation of a separate national set of reproductive health indicators would go far in reducing the present fragmentation of programs and initiatives and would increase the importance of reproductive health within the national health agenda.

RECOMMENDED DEFINITION

At its 1994 meeting, the International Conference on Population and Development defined *reproductive health* as follows:

> Reproductive health is a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes.

"Reproductive health" therefore implies that people are able to have a satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide whether, when, and how often to do so.[10]

Although any definition of reproductive health, no matter how broad or narrow, has advantages and disadvantages, the advantages of adopting the ICPD definition just quoted are compelling. The definition is positive, emphasizing health rather than disease. It is sufficiently broad so as not to exclude specific services, concerns, or groups, and it could serve as a conceptual framework that would support the development of integrated reproductive health programs in the United States. It is recognized as valid and acceptable internationally and would bring the United States into conformity with the Cairo program of action. The definition might also serve as a rallying point to inspire change, create new coalitions and partnerships, attract additional financial and political support, and positively influence the current debate about reproductive rights and freedoms in the United States. For all of these reasons, this definition of reproductive health has been adopted for the purposes of this document.

KEY CONCEPTS OF REPRODUCTIVE HEALTH

The following caveats should ideally be applied to all reproductive health services in the United States:

- Reproductive health policies, programs, and services should be comprehensive, voluntary, and non-coercive; confidential and respectful of human rights; and age appropriate, culturally sensitive, and appropriate for men as well as for women.
- Reproductive health programs and services should be accessible to everyone without regard to sexual orientation, gender, age, race or ethnicity, citizenship, geographic location, primary language, education level, physical or mental disability, marital status, income, or insurance status. Reproductive health services are essential for the entire population, male and female, and not merely for those who are childbearing or sexually active.
- Reproductive health care should include the provision of information and services that address the changing concerns related to reproductive health in youth, middle age, menopause, and later life.

Reproductive health services for any population should include (but not be limited to) the following:

- **Men's and women's health—**The population should have access to the health care, screening, and preventive services necessary to ensure reproductive health throughout the life cycle.

- **Safe and healthy motherhood—**The population should have access to appropriate health care services that will enable women to have safe pregnancies and deliveries (if desired) and to provide families with the best chance of having healthy infants.[10]
- **Reproductive tract infections and reproductive system cancers and other diseases—**Reproductive health care should include prevention, screening, and treatment of reproductive tract infections, including HIV/AIDS and other sexually transmitted diseases, and of cancers of the breast and reproductive system.
- **Fertility regulation—**The population should be informed about and have access to their choice of the full range of safe, effective, affordable, and acceptable methods of family planning. Abortion, sterilization, and basic infertility services are also a part of fertility regulation.[10]
- **Education and counseling—**Reproductive health care should include the provision of unbiased, accurate information and counseling on all aspects of sexuality and reproductive health. To ensure the reproductive health of the population, such information must be readily available and widely disseminated.
- **Developing new technologies—**Improving reproductive health entails encouraging the development of reproductive technologies as well as promoting access to and ensuring appropriate use of such technologies. Safeguards that ensure rigorous evaluation and approval, as well as informed consent, must be in place during all stages of the development and use of such technologies.

The following conditions must also be met in order to promote the reproductive health of the population:

- **Freedom from violence—**The population should be free from violence, coercion, abuse, and other harmful practices related to sexuality and reproduction.[11]
- **Freedom from hazards—**The population should be free from reproductive health hazards, including environmental toxins and workplace hazards.
- **Healthy sexuality and relationships—**The population should experience healthy sexual development and maturation and have the capacity for equitable and responsible relationships and sexual fulfillment, if desired, regardless of sexual orientation.[11]
- **Public perception—**Promoting reproductive health entails positively influencing the debate about reproductive health issues in the media, in the political arena, and among the general public in order to expand and improve access to reproductive health services. Open, positive, and accurate discussions between family and community members must be supported and encouraged in order to contribute to the reproductive health of the population.

PURPOSE OF REPRODUCTIVE HEALTH INDICATORS

The purposes for which health indicators are used generally fall into the following categories[12]:

- Describing the current and past health status of a given population
- Monitoring changes in health status over time

- Assisting in setting goals
- Holding agencies accountable for improving outcomes
- Providing evaluation or quality improvement and determining program effectiveness

The indicators chosen should allow agencies and service providers to do the following:

1. Measure progress in achieving the outcomes described by the caveats, key concepts, and definition of reproductive health
2. Identify emerging reproductive health issues and needs
3. Respond quickly and effectively to reproductive health disparities among population subgroups
4. Ensure that the reproductive health needs of the population are consistently met with quality services
5. Foster consistency in indicator definitions and data collection
6. Assess the effects of policy changes on reproductive health

To be useful, a set of indicators focused on reproductive health must give agencies and service providers the information they need to enhance the population's reproductive health. The indicators chosen should be regularly evaluated for validity and relevance and should change in response to the changing reproductive health needs of the population. Following is a discussion of the positive and negative implications of different aspects of each of the potential purposes just listed.

Measure Progress in Achieving Outcomes

A consensus must be reached on a definition of reproductive health, and this definition must be used to guide the selection of indicators. The definition, with its caveats and key concepts, provides insight into what should be measured.

A distinct disadvantage of this approach is the difficulty inherent in achieving broad consensus for any definition of reproductive health. Another is the possibility that some political decision-makers may not support U.S. participation in international initiatives; as a result, this approach could increase political vulnerability.

If indicators based on the key concepts, definition, and caveats are chosen, then the data collected can be used to help bring the United States into conformity with international initiatives toward integrating reproductive health services. Advantages of this approach include the ability to build on the strong conceptual framework provided by international work and to learn from international experience. This may increase U.S. influence in the international realm. It may also motivate U.S. policy changes aimed at improving the outcomes that do not compare well with those of other industrialized nations. In this way, measuring progress toward achieving desired outcomes may help to increase political support for domestic reproductive health initiatives.

Identify Emerging Health Issues and Needs

Indicators that identify emerging health issues and needs should be national in scope in order to allow comparison of different populations, to leverage material and political resources, and to measure the impact of major policy initiatives. From the data thus gathered, a baseline can be established that can be used to set targets. National data are key for this purpose but should not be the only data used. Because local needs may be overlooked or lost in national results, local and/or program-based indicators will be needed to fill this gap.

Respond to Health Disparities

The indicators selected should allow rapid identification of disparities. Such indicators would give policy makers and providers important data to guide decisions about funding and service allocation.

Ensure Consistent Quality Services

Indicators that measure the quality and effectiveness of services are a potentially useful management tool. They allow performance evaluation, can be used to determine performance goals or minimum standards, and enable the identification of best practices among various programs. Such indicators can also be used to substantiate the need for additional resources, to support or encourage joint public- and private-sector activities or alliances, and to foster consistency in the delivery of reproductive health services.

The disadvantages of such indicators include concerns that programs operating in vastly different contexts may be unfairly compared. Other disadvantages are the difficult methodological challenges involved in measuring the impact of specific programs. There may also be negative ramifications of program evaluation, such as funding losses. Such assessment may promote unhealthy competition between programs competing for scarce resources. The choice of reproductive health indicators will both drive and limit programs' need for information.

Both providers' and clients' perspectives on the quality of services should be included in formulating indicators. Including indicators that measure both providers' and clients' perspectives adds to the knowledge base, increases the sensitivity of data gathered, and may improve responsiveness to client concerns. Collecting information from both providers and clients may assist in identifying best practices. It also capitalizes on providers' knowledge about what works in their setting with regard to the populations they serve.

The disadvantages of these indicators include the potential for creating resentment among different provider types. In addition, clients' or providers' wants and needs may be different from research, policy, or health priorities.

Foster Consistent Definitions and Data Collection

Ensuring consistency in indicator definitions should increase the accuracy and comparability of data. Consistent data collection is a potentially powerful tool for improving overall standards of care. More accurate data allow for fine-tuning of interventions and better understanding of current needs.

The disadvantages of such indicators include the expense that results from changing preexisting data collection systems. Other disadvantages have to do with implementation issues, such as staff resistance to change. Changes in data collection can also complicate the comparison of future and past data if different indicator definitions are used. Once these changes are accomplished, however, comparability problems will recede over time. In addition, different segments of the population may have priorities that have resulted in unique definitions and data collection methods, making it potentially difficult to achieve the buy-in necessary for consistency in indicator definitions and data collection.

Consistency in indicator definitions and data collection also fosters cohesiveness among the different agencies and players addressing different pieces of the reproductive health whole. Fostering cohesiveness has several clear advantages. It saves money and transcends the tendency of various reproductive health fields (e.g., family planning and sexually transmitted disease health care providers) to strictly categorize their services by area of focus and disease state. It may also support advocacy, promote collaboration, and focus attention on reproductive health. Cohesiveness may also help to reduce frustrations at the provider level and to streamline data collection.

The disadvantages of consistency include concerns that cohesiveness might encourage stasis because it is difficult for larger groups to be as responsive as groups with smaller areas of focus. Other potential disadvantages include the possibility of creating service gaps as smaller issues are overlooked. In addition, building partnerships is difficult and time consuming, and such partnerships may not create the desired change.

Assess Effects of Policy Changes on Reproductive Health

Because legislative and political activity has an impact on reproductive health, assessing the effects of policy is an essential element of this project. Policy-based indicators provide data on which policy refinements can be based, and they can support advocacy efforts. The disadvantages of assessing the effects of policy are that it can further politicize the issue of reproductive health and it poses difficult methodological problems.

Examining the effects of policy on reproductive health may also allow guidance and tracking of advocacy efforts and funding allocations. Doing so could enhance advocacy-planning efforts, may attract funds for research, and could encourage responsiveness to specific advocacy issues, such as insurance coverage for contraceptives. Tracking advocacy efforts and reproductive health funding also helps health professionals to establish priorities, mobilize efforts, and recognize the need for additional broad-based support. Conversely, advocacy efforts have the potential to bias data collection, and indicator selection or research may be limited by current events or may be restricted to those public health issues that are most highly publicized, rather than those that are the most pressing.

SCOPE OF THE INDICATOR SET

The scope of the indicator set should be focused on reproductive health status and outcome measures, which should be positively defined whenever possible. At the same time, it is important to recognize the breadth of the many social and other factors that have an impact on reproductive health.

In defining the scope of the Reproductive Health Indicators Project, the following questions need to be answered:

- What population will be targeted?
- What information is desired, and what factors have an impact on what is being measured?
- How will the information be collected?
- Why is this information being collected, and what are its uses?

The last of these questions (i.e., the purpose of the indicators) is addressed in the earlier part of this paper. The remaining areas are discussed in the following paragraphs.

Population and Scale

Age

The conventionally used category of female reproductive age (i.e., 15–44 years) does not take into consideration men's reproductive abilities, nor does it encompass early puberty or the expansion of women's childbearing capacities into later years. If reproductive health is thought of as including sexual health, as stated previously, then reproductive health truly spans the life cycle. Predictors of reproductive health in later life include (in addition to education levels in general) receiving education about reproductive and sexual health before puberty, as well as physical activity levels and diet during childhood. In light of these issues, the indicators should be directed to people of all ages and should provide different foci for different age sets.

Gender

Men must be included as equal partners in reproductive health.[13] Fertility rates and other measures of men's reproductive health have been neglected in the past. It is therefore recommended that the indicators focus on both women and men.

Racial and Ethnic Categories

The topic of including racial and ethnic categories in the indicator set is contentious and complex. Neither race nor ethnicity alone can explain the health disparities experienced by non-whites in the United States.[14] To help ameliorate these difficulties, it is important not to confuse racial, ethnic, and geographic identities. Current racial and ethnic categories should be used to permit comparison with earlier data while allowing those categories to be critiqued.[15,16]

Socioeconomic Status

In addition to influencing health status, socioeconomic status has implications for policy and health care delivery.[17,18] A complex interplay exists among socioeconomic status, race, and health.[19] Indicators should be thoughtfully selected so as to ensure comparability with earlier data and should be sufficiently fine-tuned to yield additional data of interest.

Local, Regional, and National Data Sets

Reliable state- and county-based data are essential for informing decisions at the state and local levels and supporting advocacy efforts. In addition, consideration might be given to additional program-based categories, for example, populations served by the Indian Health Service or by Title X programs. Summarized below are the key advantages and disadvantages of developing both types of data sets.

National data sets. National data sets provide a national snapshot that is useful for policy formulation and resource allocation. National data sets also allow comparisons of international data and comparisons between regional or local and national data. The disadvantages of national data sets include the fact that national data are not always useful in guiding local action. In addition, information about small populations may be overlooked in a national data set, and the potential exists for conflict between local and national priorities.

Local data sets. Local data sets can be used to permit comparisons and state rankings, motivate local efforts, garner local resources, improve local responsiveness, and support advocacy at the state level as well as local decision-making and planning. Local data sets also allow monitoring of outcomes influenced by local programs and might encourage ownership of local problems.

High costs and funding difficulties often restrict efforts to gather local data. Given the many different local contexts, it can be difficult to compare and generalize local data sets, and sample sizes are sometimes too small to discern changes or establish associations.

Information Needs

The information needed for a national indicator set includes data on new treatment modalities, drugs, technologies, and research efforts. Indicators for this category might include the number of clinical trials underway to evaluate new contraceptive methods in a given year, or federal monies spent in a given year on research for cervical cancer.

Information is also needed on reproductive health and well-being, disease states, and functionality. This category would be made up of health status outcome measures, including those that have been shown to support or predict reproductive health and well-being.

A category on reproductive health services would encompass data about providers and clients, service delivery, and best practices. It would also include information on access to services and the factors that affect access, including education, culture, primary language,

socioeconomic status, insurance, local availability of services, legislative climate, hospital mergers, training of clinicians, disability, and discrimination.

Social and Other Factors

One of the challenges inherent in formulating a national indicator set is the need to encompass, categorize, and quantify all of the myriad and diverse factors that affect reproductive health. To that end, it is recommended that a workable and limited set of indicators be developed, recognizing that a wide variety of factors play a role in reproductive health. One way to develop such a set might be to focus on the measurable factors that are most amenable to intervention. These factors can be roughly categorized as follows:

- Specific needs for reproductive health services and/or protections, such as those of the gay, lesbian, and transgender communities; persons with disabilities, HIV/AIDS, substance use disorders, and/or mental illness; adolescents; incarcerated populations; and immigrants
- Ethnic/racial disparities

- Participation in public life while bearing and raising children—occupational health protections, child care, and parental leave policies, as well as/ the reproductive health policy and legislative climate
- Environmental factors (e.g., socioeconomic status, violence, nutrition, pollution)

Data Collection

The following recommendations related to the scope of data collection should be taken into account during the process of indicator selection:

- Coordinate local, regional, and national efforts.
- Coordinate public- and private-sector efforts.
- Have in place mechanisms for public- and private-sector cooperation.
- Select data that are being routinely collected at the local, state, and national levels.

CHAPTER 2:

OVERALL DESIGN, STRUCTURE, AND FRAMEWORK

The development of a set of reproductive health indicators requires an overall structure and design that corresponds with the broad definition of reproductive health and the purposes and scope of the Reproductive Health Indicators Project as presented in Chapter 1. Carrying out this charge requires development of the following:

- A conceptual framework or model to guide the selection and analysis of reproductive health indicators
- A procedural framework for using the conceptual model and other resources to select indicators

Background information about and recommendations for each of these products are reviewed in this chapter.

BACKGROUND

Conceptual Framework

Within the context of the Reproductive Health Indicators Project, a conceptual framework is a blueprint that depicts the relationships among indicators. Conceptual frameworks, or models, are commonly used in research for two reasons: 1) to describe known relationships among variables and 2) to hypothesize relationships under investigation. Models constructed for descriptive purposes are useful in the development of sets of related indicators that are capable of "telling a story"about reproductive health in a given population. A model helps to guide the selection of indicators in a way that minimizes the probability of omitting a key concept from the indicator set while setting clear boundaries for the scope of the set. At the same time, a model does not require the selection of any specific indicators or any predetermined number of indicators, thus allowing the developers of the indicator set a great deal of flexibility within the framework.

Because there are many potentially applicable conceptual frameworks from which to choose, it is necessary to identify those qualities that are of major importance for reproductive health indicators. The following five qualities are considered optimal:

1. **Relevance to the purposes and scope of reproductive health indicators—**Five of the six purposes stated in Chapter 1 (see "Purpose of Reproductive Health Indicators," Chapter 1) offer guidance for developing the components of the conceptual model. The model should support the development of indicators that will do the following:

    - Measure progress in achieving outcomes described by the key concepts, caveats, and definition of reproductive health
    - Identify emerging reproductive health issues and needs
    - Identify disparities among population subgroups

- Identify reproductive health needs of the population and the extent to which they are met with quality services
- Assess the effects of policy changes on reproductive health

The model should also conform to the proposed scope of the indicator set by emphasizing measures of reproductive health status and outcomes while reflecting the breadth of social and other factors that have an impact on reproductive health.

2. **Consistency with requirements of the Government Performance and Results Act—** The Government Performance and Results Act (GPRA)[1] emphasizes the use of indicators for monitoring federally funded programs by focusing on inputs, processes, and outputs. The GPRA has a special interest in measuring intervening outcomes—those changes in individuals or systems that are expected to occur as a result of organized interventions but that take place before the ultimate outcome goals of the intervention can be measured (Manning B, HHS Performance Plans, OPA Meeting Presentation, May 23, 2000).

3. **Adaptability to reproductive health content or domains—**The model should be compatible with existing reproductive health indicators, such as those specified in *Healthy People 2010*[2] and other widely recognized indicator sets in the field. At the same time, the model should provide guidance for the development of indicators that are not currently available or used.

4. **Documentation in the literature of relationships depicted in the model—**The model should be derived from solid research that confirms, rather than hypothesizes, relationships among domains and/or variables.

5. **Intuitive logic, simplicity, and understandability—**Because reproductive health indicators will be disseminated to people of many backgrounds, the model on which they are built should facilitate, not inhibit, their understanding and application.

In reviewing the qualities just described, it can be seen that all of these requirements cannot be satisfied to an equal extent. For example, items 1 and 2 suggest that many domains should be included in the reproductive health indicators model. Given the number of possible reproductive health conditions of interest and the complex relationships among the factors that contribute to them, the model could be extremely complex. Yet item 5 specifically calls for simplicity and offers a compelling rationale for doing so. In addition, item 4 requires documentation in the literature of relationships in the model, yet many interventions that are in operation—some of which should be monitored by reproductive health indicators—have not been systematically evaluated and thus have not been published. These inconsistencies present challenges to find ways to address each quality while recognizing that most of them may not be fully satisfied.

Procedural Framework

In addition to a conceptual framework, developing an indicator set also requires guidelines that help those using the model to systematically review options and to select or develop indicators. The second task in developing a set of indicators is thus to construct a procedural

framework. As is true of the conceptual model, certain qualities are required of the procedural framework:

- Systematic sequencing of development phases to allow for adequate attention to each type of indicator
- A primary focus on reproductive health status, with linkage to other indicators
- Use of existing indicators whenever possible
- Allowance for a core set of indicators selected from the larger set
- Consistency with other federal government activities and requirements (e.g., GPRA, *Healthy People 2010*, Maternal and Child Health Bureau Performance Measures)

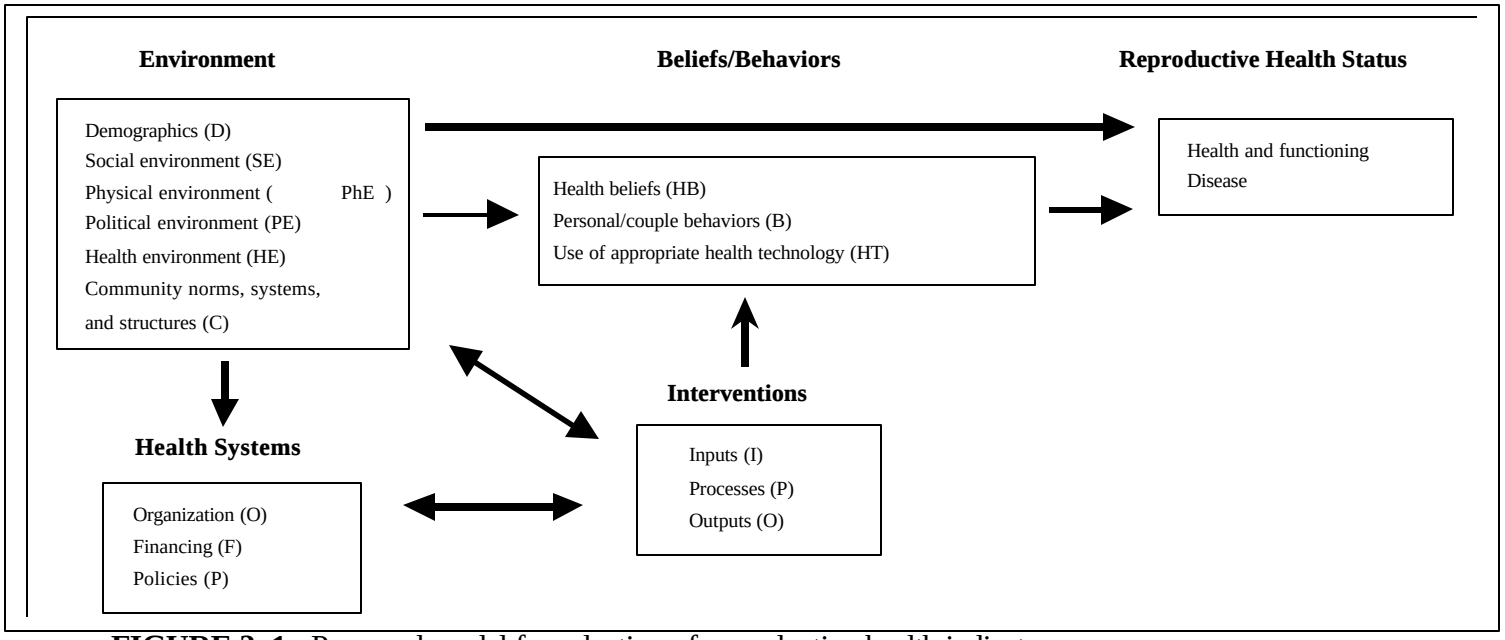

FIGURE 2–1. Proposed model for selection of reproductive health indicators.

RECOMMENDATIONS

Proposed Conceptual Model

Figure 2–1 shows the model that is proposed to guide the development of reproductive health indicators. This model is derived from well-established models used in the field of health services[3,4] and more recent work by experts in reproductive health and maternal and child health[5–9] (Middleburg M, Hogue C. Reference materials for reproductive health program management course, 1999). The proposed model has been designed to be consistent with the information needs of GPRA[1] plans and reports (Manning, 2000), *Healthy People 2010*,[2] and the purpose and scope

The model includes 17 domains, which are organized under five headings that represent the key aspects of reproductive health:

1. Reproductive Health Status
2. Beliefs/Behaviors
3. Environment
4. Health Systems
5. Interventions

The heading "Reproductive Health Status," shown on the far right of Figure 2–1, represents the focus of the conceptual framework. The other four groups contribute to this group of domains. The domains included under the Environment and Beliefs/Behaviors groups influence the levels and quality of reproductive health. Interventions are designed to modify some of the factors in the Environment and Beliefs/Behaviors groups so that reproductive health improves. Interventions that involve health services (in contrast to other types of services) are highly dependent on the health systems in which they must operate. At the same time, some domains in the Environment group affect the existence and characteristics of those in the Health Systems and Interventions groups. In Figure 2–1, arrows provide a general indication of how the groups of domains contribute to one another.

The model represented in Figure 2–1 is, in many ways, an oversimplified depiction of the complex interactions among the factors that affect reproductive health. However, the model provides an essential framework for selecting indicators from an extensive array of possibilities. Considering indicators across 17 domains ensures adequate breadth. Within each domain, many optional indicators must be carefully considered. This deliberate process will promote the development of a highly meaningful indicator set that should be adequate in both breadth and depth. Each of the groups of domains is described in more detail in the following paragraphs.

Reproductive Health Status

The Reproductive Health Status group (see Figure 2–1) is the major focus of the model. Consistent with the broad definition of reproductive health presented in Chapter 1, this group includes both positive and negative perspectives within two domains—1) Reproductive Health and Functioning and 2) Reproductive Diseases. These domains encompass a wide array of indicators. For example, health and functioning could include fertility, breast-feeding, and domestic tranquility; examples of reproductive diseases are HIV and other sexually transmitted diseases, infertility, malnutrition, and cancers of the reproductive system.

Beliefs/Behaviors

Reproductive health is a function of many diverse domains. A set of domains that applies primarily to individuals, couples, and families is grouped under the heading "Beliefs/Behaviors." These domains include reproductive health knowledge, attitudes, and values (e.g., values about family size); personal and couple behaviors (e.g., adequate intake of folic acid before and during pregnancy, multiple sex partners); and use of health technology that has been demonstrated to influence reproductive health status (e.g., effective contraceptive methods). The arrow between this group and the Reproductive Health Status group indicates a close, often direct, association.

Environment

The domains in the Environment group can have a direct influence on reproductive health (e.g., toxic exposures) or an indirect influence through beliefs and behaviors. These domains represent conditions of communities or systems, rather than of individuals, couples, or families. Each of these domains is briefly described below:

- **Demographics—**Age, gender, racial and ethnic distribution
- **Social environment—**Economy and prosperity, family structure, social class, occupation, education
- **Community norms, systems, and structures—**Religion, racism, social service system, educational system, communication systems
- **Political environment—**Policies, advocacy, political climate
- **Physical environment—**Housing, safety, toxic exposure
- **Health environment—**Biological susceptibility, communicable disease levels, other medical conditions

The domains in the Environment and Beliefs/Behaviors groups are sufficiently inclusive to serve as a blueprint for developing indicators of the important factors that contribute to reproductive health. However, these domains by themselves do not account for two key aspects that are of interest to the OPA and that are necessary to the development of indicators: 1) health systems and 2) organized interventions. The domains in these two groups often modify factors in the Environment and Beliefs/Behaviors groups, thus affecting reproductive outcomes. These two additional domain groups are described below.

Health Systems

The domains under the Health Systems group are as follows:

- Organization of the system (e.g., distribution of providers and facilities)
- Financing (e.g., insurance coverage of services and populations)
- Health policies (e.g., legislation that is supportive of reproductive health services for young men)

These domains are often influenced by factors within the environment. Strong political support of public infrastructures, for example, contributes to the existence of health systems with the breadth to address a variety of community needs. In turn, the domains in the Health Systems group have major effects on interventions. Thus, the manner in which the health system finances interventions can promote or inhibit the integration of services across genders and programmatic categories.

Interventions

Organized interventions include programs offered through Title X as well as those provided by other government and non-government agencies. Intervention domains are the classic

components of the general systems theory[10] that is widely used to describe health services[7,11] (Manning, 2000): inputs, processes, and outputs.

Inputs. Inputs are the elements that must be available for an intervention to operate. Many inputs are external to interventions. For example, health system capabilities, insurance coverage, and community norms influence what types of interventions are offered, in what form, and to whom. These external inputs emanate from the domains in the Environment and Health Systems groups and are acknowledged in the model by the arrows from these two groups to the Interventions group. Interventions also have inputs that are internal, or specific, to their efforts. These would include financial resources and organizational structure (e.g., infrastructure, integration with other interventions and service structures, and partnerships).

Processes. Processes are activities undertaken by an intervention to reach its objectives, such as delivery of clinical services, preparation of educational materials, and targeted communication with legislators and the public.

Outputs. In turn, processes produce outputs, or proximate effects. If an intervention's process consists of clinical service delivery, then outputs might include the numbers of clients seen and the quality of services received. If an intervention involves collaboration among local agencies to offer integrated reproductive health services, the output may be opening an integrated service site. If the process involves educating the state's legislative community about the reproductive health needs of a population group, outputs would include improved understanding by the legislators.

In the model, arrows emanating from the Interventions group indicate intended effects on factors within the Environment, Health Systems, and Beliefs/Behaviors groups. These effects are the intermediate outcomes of the interventions. For the examples cited above, intermediate outcomes would include the use of effective contraception (for a clinical service intervention), increases in receipt of all types of screening tests by women and men (for an integrated services intervention), and enactment of policies that ensure services to specific population groups (for an intervention designed to educate legislators). Measurement of intermediate outcomes is becoming increasingly recognized as an important task (Manning, 2000), because changes occur at this level before they can be measured at the level of reproductive health status, the improvement of which is the desired outcome of interventions.

Proposed Procedural Framework

The conceptual framework described above provides a basis on which to develop reproductive health indicators. The entire development process should involve three interdependent but sequential phases. Phase 1 is development of Reproductive Health Status indicators. Since these are the most essential indicators, they should be fully developed and perhaps pilot tested before the second phase begins. Phase 2 involves development within the Environment, Beliefs/Behaviors, Health Systems, and Interventions domains. Because all of these domains imply some type of action, they are henceforth called "Reproductive Health Action indicators" in this document. When development of both reproductive health status and action indicators is completed, a core set of indicators should be selected from the larger set. This will constitute Phase 3. Several steps are required to complete each of these phases.

Phase 1: Reproductive Health Status Indicators

Development of reproductive health status indicators involves the following seven steps:

1. Operationalize the broad definition of reproductive health.
2. Reduce the number of concepts.
3. Identify potential indicators.
4. For each concept, compare the candidate indicators according to relevant criteria.
5. Select indicators that best meet the criteria.
6. Consider new measures.
7. Complete the description of characteristics of the indicators.

Each of these steps is discussed briefly below.

Operationalize the broad definition of reproductive health. Step 1 is accomplished by identifying the Reproductive Health Status concepts for which indicators are needed. To develop precise indicators, the broad definition of reproductive health must be made more specific. For example, the description given in Chapter 1, "a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes," may be operationalized to include concepts of health and functioning such as fertility, nutritional status, health during pregnancy, and pregnancy outcomes. Concepts of reproductive diseases might include infertility, sexually transmitted infections, genetic diseases, and other diseases of the reproductive organs (e.g., testicular cancer).

Reduce the number of concepts. If the number of concepts in each domain is thought to be too large, it may be reduced to a manageable size by systematic elimination on the basis of specified criteria. These criteria might include the condition's importance (in general and within such key constituencies as specific age groups, genders, and focus populations), modifiability, and political vulnerability.

Identify potential indicators. For the remaining concepts, candidate indicators are identified from existing lists, such as the summary that OPA has begun to formulate (OPA, *Selected List of Currently Identified Reproductive Health Indicators*, 1999). For example, the concept "fertility" could have several candidate indicators, such as fertility rate, pregnancy rate, induced abortion rate, and fetal death rate, and there could be more than one way to measure each of these indicators. The list of candidates could be further expanded if qualifiers, such as whether a pregnancy was intended, are incorporated into the indicators.

Compare candidate indicators. For each concept, the candidate indicators are compared according to criteria such as the following, which have been adapted from the World Health Organization's work on selecting national and global indicators[12,13]:

- **Scientific robustness—**Validity, specificity, sensitivity, reliability
- **Usefulness—**Ability to act as a "marker of progress" toward improved reproductive health

- **Ability to be understood—**Ease of definition, description, and interpretability in terms of reproductive health status
- **Accessibility—**Readily available in a useable format at appropriate time intervals and at reasonable costs
- **Representativeness—**Adequately encompassing all issues or population groups
- **Cultural competence—**Reflecting conditions of salience to one or more focus populations for which reproductive health indicators are being developed
- **Consistency—**Potential for program and interagency consistency in construction of indicators
- **Ethics—**Ethical gathering, processing, and presentation of data

These criteria are discussed in greater detail in subsequent chapters and in Annex 3 of the World Health Organization's *Monitoring Reproductive Health: Selecting a Short List of National and Global Indicators*.[13]

Select indicators that best meet the criteria. Using a systematic process for weighting and ranking alternatives, select the indicators that most closely match the criteria.

Consider new measures. In cases in which no indicator is available for a critical concept, propose recommendations for the composition, collection, and reporting of a new measure.

Complete the description. For each indicator selected, provide the following information: formula, stratification factors (gender, age, focus population), recommended data source(s), and geographic level of application (national, state, etc.).

Phase 2: Reproductive Health Action Indicators

The development of Reproductive Health Action indicators involves a few more steps than the process just described, because the concepts underlying these indicators must be linked to the Reproductive Health Status indicators. Each step is listed below and is followed by a brief description.

1. *For each reproductive health status indicator, identify contributing factors* from current, scientifically sound research. In many cases, diagrams of causal relationships among variables, consistent with the Environment, Health Systems, and Beliefs/Behaviors domains, are available in the literature. Experts in each area of reproductive health status should be involved in this step.

2. *For each reproductive health status indicator, identify interventions used to modify the contributing factors* in the Environment, Health Systems, and Beliefs/Behaviors domains. For each intervention, identify key inputs, processes, and outputs. Interventions should include Title X programs as well as other programs and interventions that have been designed to address each reproductive health status condition for which an indicator has been selected. The information required is available from the interventions, usually embedded in their stated objectives. If evaluations of interventions have been conducted and published, key information is available in the literature.

3. *Develop a concept map for each reproductive health status indicator.* Concept maps, like those shown in Figures 2–2 and 2–3, place the concepts and relationships discovered through research within the simpler framework of Figure 2–1.

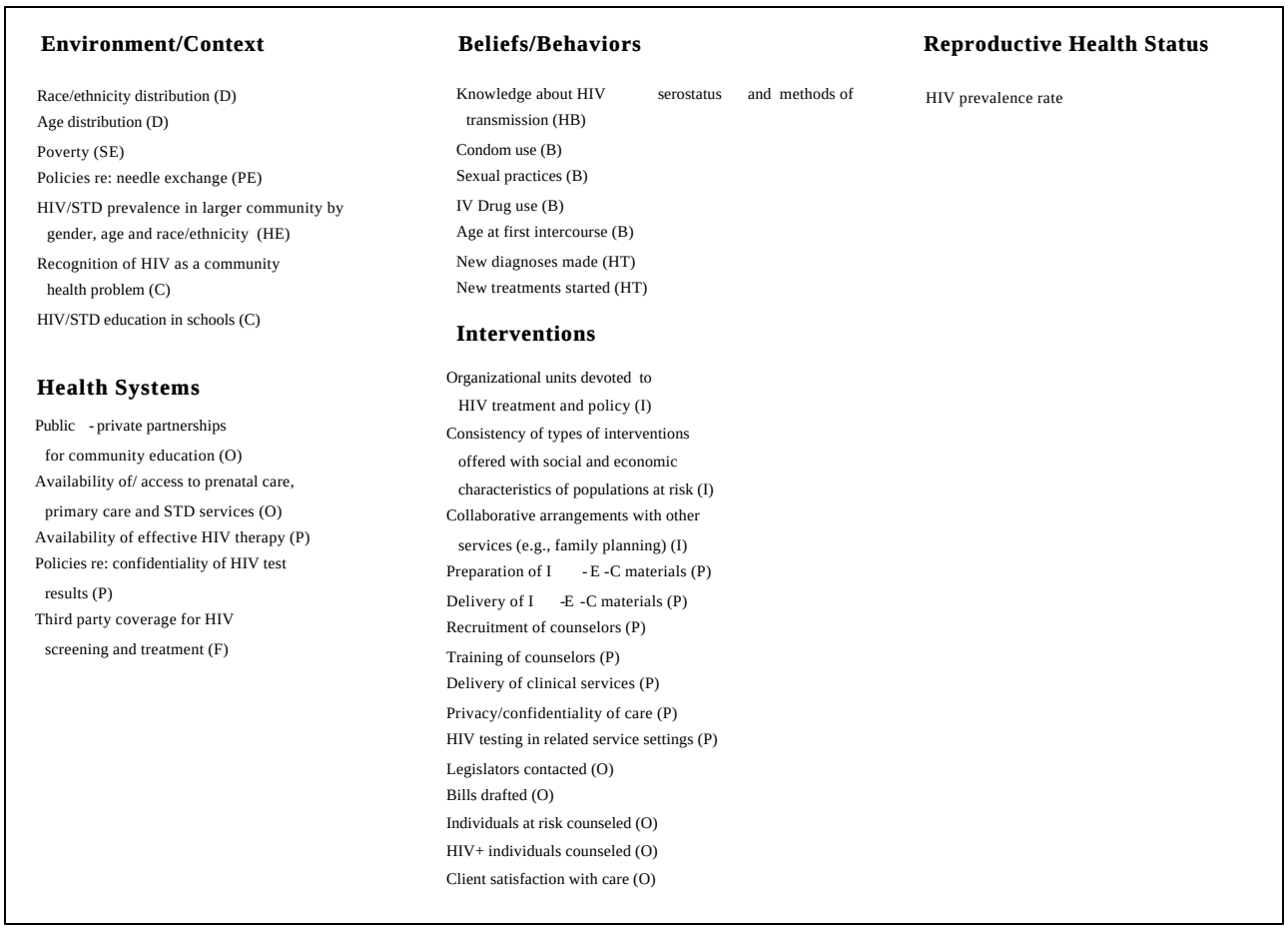

FIGURE 2–2. Illustrative concepts for indicators of HIV prevalence. Letters in parentheses refer to domains in Figure 2–1. Concepts derived from *Healthy People 2010* Focus Area 13.[2]

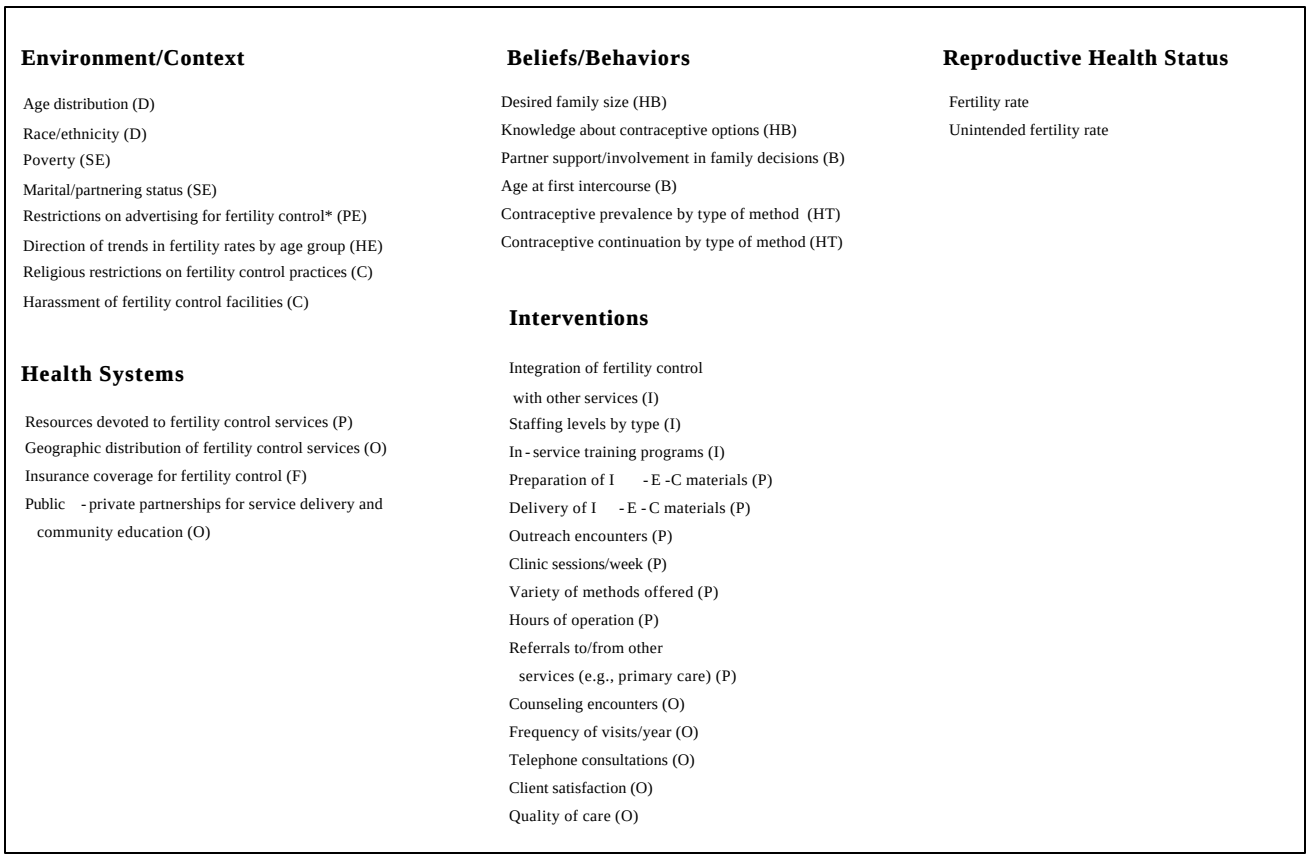

FIGURE 2–3. Illustrative concepts for indicators of fertility. *Fertility control* includes contraception, abortion, and abstinence. Letters in parentheses refer to domains in Figure 2–1. Concepts derived from *Healthy People 2010* Focus Area 9.[2]

4. *Reduce the number of concepts to a manageable set*, keeping in mind that the reproductive health indicators are intended to be used to monitor key events and conditions. One indicator in each relevant domain for each concept map will be sufficient in many cases. These may be selected from a larger pool by applying criteria such as strength of association with the reproductive health measure, modifiability, usefulness in more than one concept map, and political vulnerability.

5. *Identify candidate indicators for each concept.* For each concept in the reduced set, identify candidate indicators from existing lists, such as the summary that OPA has begun (OPA, *Selected List of Currently Identified Reproductive Health Indicators*, 1999).

6. *Compare the candidate indicators for each concept according to specific criteria*, such as those adapted from the World Health Organization,[12,13] as described above.

7. *Select indicators that best meet the criteria.* Select indicators that most closely meet the criteria, using a systematic process for weighting and ranking alternatives.

8. *Consider new measures.* In cases in which no indicator is available for a critical concept, propose recommendations for the composition, collection, and reporting of new measures.

9. *Complete the description of characteristics of each indicator.* For each indicator selected, provide information on formula, stratification (gender, age, and focus population), recommended data source(s), relationship (with documentation, as appropriate) to reproductive health status indicator(s), and geographic level of application.

Phase 3: Core Set of Indicators

The core set of indicators should be selected from both Reproductive Health Status and Reproductive Health Action indicators. Core indicators should be of great importance to reproductive health. They should represent key concepts in the definition from the 1994 International Conference on Population and Development in Cairo (e.g., male representation, specific types of health care, access to the full range of care components), as described in Chapter 1, and should include all critical domains in the model. Although a specific number of core indicators is not recommended, the number should be relatively small to encourage their widespread utilization.

Related Issues

A few other procedural issues are important to consider. First, developing the set of reproductive health indicators is a very complicated task. It should be undertaken within a realistic time frame by teams of individuals with specific expertise. The three-phase procedure described above is intended to promote logical sequencing while encouraging reasonable time frames. In light of the differing complexity of each phase, Phases 1 and 3 might be assigned 1 year for completion, whereas Phase 2 could be a multiyear project. Alternatively, the phases could also be accomplished through separate contracts, in which case Phase 2 could be completed in a shorter period by several teams working concurrently.

Second, although adequate time should be allocated for the development of the indicators, efficiency should also be a high priority. The development teams should rely heavily on the excellent work that has already been done for *Healthy People 2010*,[2] the EVALUATION Project,[5–7] and other related efforts. By building on these products, the final set of reproductive health indicators will not only be developed in a relatively shorter time but will also be as consistent as is reasonably possible with these other important works.

A third related issue is the composition of the teams of indicator developers. The development process requires a wide range of expertise and representation. The teams that develop each concept map should differ, each one including individuals who are actively engaged in research on the reproductive health status indicator of interest and on interventions designed to address the condition. These teams should also include people who have designed and executed the interventions. Once the concepts are selected, team composition may shift to be more representative of individuals who have expertise in the technical and practical measurement issues related to the concepts. Throughout the process, representatives of user groups of all types, such as state and local health units, federal agencies, health planning organizations, and managed

care organizations, should be involved. These participants will play keys roles in focusing on those measures that are of greatest value to their respective fields.

Finally, the process for selecting and developing a set of reproductive health indicators will involve a review of many indicators that will not be part of the final set. Some of these indicators have limited utility and should be phased out. As a result, a parallel process for assessing these indicators, with the intention of eliminating ones that have become unnecessary, is recommended.

CONCLUSION

Applying the conceptual model and procedural framework proposed here will lead to the development of a range of indicators that reflect reproductive health status and the key factors that contribute to it. Several examples of the uses of potential indicators are described in Table 2–1. As the table suggests, once fully developed and operational across geographic areas and population groups within the United States, the indicator set can be used to track progress in reproductive health and to encourage a broader understanding of its context and the ways in which specific issues and problems are addressed, thus fulfilling the purposes proposed in Chapter 1.

TABLE 2–1. Examples of Uses of Reproductive Health Indicators Derived from the Proposed Conceptual Model and Procedural Framework

Indicator Use	Example
Indicators of reproductive health status can be tracked over time, across areas, and among populations. Disparities will be clearly apparent and progress toward 2010 objectives can be noted.	Compare trends in the prevalence of HIV infections among females 13–24 years of age, 2000–2010, by selected populations.
Reproductive health status indicators can be submitted to a weighting and ranking process such as that described by McGinn, et al.,[9] to determine which are most appropriate for a community or state to address.	Compare rates of unintended pregnancy, HIV infection, reproductive cancers, and infertility within a jurisdiction according to severity, magnitude, and social/human rights effects in order to establish level of priority.
Important factors that contribute to reproductive health status can be monitored, accounted for in intervention design, and used to defend requests for financial support.	Monitoring cultural factors that contribute to early adolescent pregnancy, such as expectations for adolescent marriage, can help justify funding requests for different types of interventions in different locations.
Indicators of Environment, Beliefs/Behaviors, and Health Systems domains can be compared across time, population groups, and areas to identify populations at increased or decreased risk of reproductive health problems.	**1.** Track trends among women in need of family planning services by year and location. **2.** Compare rates of insurance coverage for fertility control services across states and cities.
Interventions to address specific reproductive health conditions can be compared across areas and populations to identify disparities in service availability and use.	Compare existence of programs that screen for prostate cancer and number of screenings done in each across communities in a state.
Key inputs, processes, and outputs of an intervention can be compared with stated objectives or with the same indicators from other interventions of the same type. This information can be used in GPRA plans and reports.	**1.** Compare Title X programs for evidence of delivery of integrated services (e.g., memoranda of understanding, combined clinics) across cities with similar characteristics.

	2. Track the percentage of people served by Title X across jurisdictions and time and compare these with program objectives. **3.** Compare the percentage of women age 18 and older who have received a Pap test in the past 3 years across income and education groups.
Costs associated with interventions can be compared in various ways to demonstrate how funds are used.	Compare cost/test for each cancer screening program (e.g., breast, cervical, testicular, prostate) across regions of the country.
Intervening outcomes of interventions can be monitored on a regular basis and used to justify interventions before evidence of effects on reproductive health outcomes can be generated. GPRA is also very interested in this level of information.	With HIV as the reproductive health status indicator of interest, track the percentage of unmarried, sexually active males who use condoms.
The effects of policy changes on indicators in all domains can be tracked by monitoring selected indicators over time.	Compare the prevalence of neural tube defects before and after widespread implementation of folic acid supplements in common foods.
Monitoring indicators will suggest specific hypotheses that should be tested with rigorous research methods to validate or refute existing practices.	Comparing service characteristics (e.g., availability of free Pap tests) and outcomes (e.g., Pap tests done, positive test results, positive findings with follow-up care) across population groups may point to disparities that should be investigated with more powerful research methods.

CHAPTER 3:

SCIENTIFIC, TECHNICAL, AND IMPLEMENTATION ISSUES

The task of agreeing on a definition of reproductive health, though challenging and important, is only the very first step in developing a set of indicators for reproductive health. Once a definition has been established, there remains much work to be done to make the definition operational by developing indicators that reflect the components of reproductive health. This task leads to still another step—ensuring that the indicators are measured and used appropriately. These latter two steps are considered in this chapter, in which is discussed the scientific and technical factors that must be addressed in selecting, defining, and using the indicators and the details of implementing the indicators program.

Many of the scientific and technical issues that arise in this task are common to other types of measurement and data gathering. Such key issues are reviewed here first, and areas of special relevance to this undertaking are noted. However, the information in this chapter is no substitute for the scientific expertise that will be needed when indicators are finally defined and measured.

Other issues are specific to which indicators will be selected and how the project will be implemented. There are many existing sources of data covering this topic, as well as experienced experts who know the strengths and limitations of these data, within the field of reproductive health. All such data sources have not been reviewed in the development of this chapter, and such experts will be an important resource for indicator development once potential indicators have been identified. Projects to select, produce, and use indicators in other areas have demonstrated the importance of early and ongoing attention to communication and coordination throughout the implementation process. From these experiences, some important issues can be identified for integration into the reproductive health indicator project. These issues are reviewed in the second part of this chapter.

SCIENTIFIC AND TECHNICAL ISSUES

The first step in defining indicators is to decide which indicators are needed and for what purpose. Only after these decisions have been made can it be determined which data items are needed to produce the indicators. Health *status*, or outcome, indicators (see Glossary) can be useful for focusing public and programmatic attention on high-priority areas, identifying gaps between current status and goals, and monitoring various aspects of reproductive health across the nation or in a particular population subgroup.

The basic conceptual and scientific criteria for health status indicators include the validity, reliability, and availability of data; the timeliness of data collection, and the production and/or availability of indicators. *Process* indicators (see Glossary), which measure inputs or activities that will improve reproductive health status, must meet these criteria as indicators. In addition, there also must be evidence about how the specific inputs will affect the relevant outcome indicator.

Validity

In formulating the reproductive health indicators, discussion with various stakeholders and experts will be needed to ensure that the proposed indicators are valid, that is, that they accurately capture the components of reproductive health. In some cases, it may not be feasible to use a particular, "ideal" indicator, owing to measurement constraints or insufficient data. For example, it may be necessary to use a small number of sexually transmitted diseases (STDs) for which data are available and reliable as a proxy for surveillance of all STDs known to occur in a population.

If there is a close association between program inputs and outcomes, process indicators might be appropriately used as proxies for or complements to status indicators. Because they are often more directly related to program actions than are outcomes, process indicators can also be useful for monitoring and directing service delivery and other interventions. For example, because many women and men may unknowingly have an STD, the proportion of a program's sexually active clients who are screened (and treated, if positive) for STDs is a process indicator that has been shown to be effective in lowering the incidence of STDs.

However, other factors that may be more or less within a program's influence (such as condom use or number of sexual partners) also affect health status. Process indicators must be selected with great care and must be based on evidence of their independent impact on health outcomes. Attention must also be given to alternative influences and variations in impacts in different contexts. The multiplicity and complexity of personal, social, economic, and programmatic factors that affect reproductive health status suggest that careful consideration must be given to the selection of process indicators.

Reliability

The measurement or calculation of an indicator must be consistent across groups, such as state, population, or program, as well as over time. This basic criterion has very high priority precisely because the value of reproductive health indicators lies in the ability to make comparisons across groups and over time. If measurement of indicators is not reliable, it will be difficult to determine whether reproductive health status has improved and whether certain geographic areas or subgroups need more or less assistance in meeting goals.

The accurate and consistent measurement of indicators presents great challenges, especially when data are collected and tabulated by a variety of entities. There are likely to be differences in how definitions are interpreted and data are gathered, as well as in computational approaches. These differences can result in inconsistency in seemingly identical indicator scores, which will not be obvious from the indicator value alone. Careful attention must therefore be given to the technical details and potential problems inherent in the use of each indicator. Such efforts are most likely to be productive when they include the active consultation and involvement of the people who are responsible for gathering and processing the data that form the indicator score.

To achieve consistency in indicator measurements, the indicator must be clearly defined. Potential ambiguities in the definition and its measurement need to be identified and resolved,

and clear directions are needed as to how to compute the indicator score. These directions should include issues such as how to handle missing data and definition of invalid fields. In some cases, the data source must be stipulated, because reporting from different sources may differ. For example, information on racial and ethnic status may be obtained from personal reports or provider observation, and information on gestation may be derived from the mother or from physicians' records. When different areas or groups obtain data from different sources, comparisons of their indicators may be misleading because they are not measured consistently.

Data Considerations

Issues surrounding data are necessarily intertwined with those concerning specification of indicators, because the ways in which indicators are defined and selected depend in large part on the availability of and capability to collect data. Limitations or gaps in the available data may make it impossible to measure a desired indicator or to do so in a valid and reliable manner. Moreover, because data for different indicators are likely to be obtained from different sources, issues such as stakeholder involvement, planning, and provider training should be considered both for each indicator and in general.

For these reasons, although they are described here in separate sections, specification of indicators and planning for data collection and indicator calculation are not successive steps but rather concomitant processes that must be coordinated. For each indicator, a number of questions about the "what, where, and how" of identifying data sources should be asked and adequately answered. These questions are posed in the following paragraphs.

Types of Data

What types of data are needed to measure each indicator? For example, is a complete count necessary, or can the information be obtained by using data that are based on a sample of the population or the universe of interest? Can the indicator be measured using only one source of data, or are multiple sources necessary (such as the need for census data, vital statistics data, and even survey data to create a composite measure of the pregnancy rate)?

Availability of Data

Are the data already available? If not, what must be done to collect or obtain them? Answering this question may entail considering the cost implications of gathering data and identifying who is responsible for bearing those costs. It may also involve setting up relationships between organizations to obtain access to and permission for the use of data that have already been collected. In addition, if some data are being used for multiple purposes by multiple organizations, it may be necessary to set up safeguards to ensure the confidentiality of those who originally provided data for only one purpose. In order to accurately measure the desired indicator, it may be necessary to make changes in ongoing data collection systems; to develop data gathering, processing, and use capacity on national, state, and local levels; and to increase the staff needed to direct and support the implementation of reproductive health indicators. These changes may have implications for using indicators to monitor time trends that must also be considered if, for example, different items are collected in different ways at different times.

Sources of Data

What are the advantages and disadvantages of using different sources of data for each indicator being measured? For example, if data from a local area are used, an obvious advantage is the ability to present information for local subpopulations. If the data are not consistently collected across all areas, however, then aggregate or national measures may be difficult to obtain. In other instances, client records may be a useful source of data because this information is already being collected. These data, however, apply only to individuals who have sought services and do not include the characteristics or experiences of those who have not done so. As another example, national sample surveys and census population data are important sources of rich data but are not available on an annual basis. Indeed, intercensal estimates can be misleading for populations and areas that are changing at a rapid pace. It is therefore important to assess how frequently specific types of data will be needed. In addition, the sample sizes and sampling methods used for national sample survey data often do not allow the data to be tabulated according to more localized areas (e.g., states). Data may also be available from other organizations that use them for similar (though not identical) purposes, such as Health Plan Employer Data and Information Set (HEDIS) measures. Use of such data, however, may present difficulties in adapting those measures to the specific purposes of the indicator desired for other purposes.

Examples of the strengths and limitations of a variety of data sources are shown in Table 3–1 and illuminate some of the issues that must be considered in constructing an indicator set. Although an assessment of any data item's usefulness depends on how it might be used in an indicator, it is possible to identify some of the advantages and disadvantages of some specific data sets that are commonly used in the field of reproductive health. Although the following examples are illustrative rather than final evaluations, it can be useful to identify some of the issues and problems that will need to be considered in moving from the concept to measurement of reproductive health indicators.

TABLE 3–1. Strengths and Limitations of Potential Data Sources for Reproductive Health Indicators

Strengths	Limitations
Vital Statistics Natality Data	
• Quality is excellent for many components. • Cost-effective; marginal cost of tabulation is very low, and data are publicly available. • Data are available for (some) small groups. • Data are produced annually. • Consistent definitions and methods over time allow comparisons and merging of years for more stable estimates. • Reliable at levels of states and large	• Quality is weak or poorly evaluated for some components. • Not flexible; difficult to add or change items. • Narrow definitions of subgroups; no economic status measure. • Racial and ethnic classifications are questionable and vary by source of information. • Persons are not linked to program use. • Decentralized (state) data collection requires much discussion, review, and

countries.	cooperation from independent bodies.
Family Planning Annual Report: Title X family planning program data	
• Ongoing data collection system. • Data are produced annually. • Potential for periodic review and change. • Grantee based, but also tabulated by state. • Units collecting and reporting data have a potential (funding/financial) stake in the results. • Describes service users, i.e., linked to program input.	• Cross-tabulations, not raw data, preclude cross-tabulation in different ways. • Providers reporting data have competing priorities, such as service provision and other reporting requirements from other funders. • Changes in items require changes in multiple provider record and data systems. • Inconsistency in collection of data; definitions are inconsistently interpreted. • Grantee based. • Decentralized data collection requires working changes through many layers to implementation and training and offers opportunity for differences in interpretation and data gathering. • Units collecting and reporting data have a potential (funding/financial) stake in the results. • Describes service users, not the general population and not nonusers. • Captures information only about service use; no information on behavior/outcomes after received service.
National Survey of Family Growth	
• Existing survey. • Collects individual-level data, which can be tabulated in different ways. • Population based; representative of civilian noninstitutional population. • Self-reported; items cannot be verified. • High quality; personal interviews collected in standardized ways by trained interviewers. • One organization directs/controls.	• Fielded at irregular, multiyear intervals, not annually. • Costly. • Obtaining adequate numbers for small subgroups requires more funding than has been available. • Does not include some special populations, such as military, incarcerated, or homeless, but could be expanded to include them with added resources. • Does not identify respondents by risk status, such as drug users. • Some sampled individuals will not participate in the survey or respond to specific questions. • Requires parental consent for minors.

	• No local or state data. • One organization directs/controls.
Pregnancy Risk Assessment and Monitoring System	
• Existing survey. • Content is relatively flexible. • State-based data. • Individual-led data. • Population based/representative. • All births. • Self reported, with follow-up. • Can compare some items with birth certificate information. • Includes behavioral data.	• Not all states participate. • Access to data is limited. • Obtaining adequate numbers for small subgroups requires more funding than has been available. • Data are self-reported. • Some sampled individuals will not participate in the survey or respond to specific questions. • Surveys only women who have had live births.

Considered here are four types of existing data sources:

1. Natality Data, collected and compiled by state and federal Vital Statistics agencies
2. The Family Planning Annual Report, compiled from grantees that receive family planning grants from the Title X program
3. The National Survey of Family Growth, a personal interview survey carried out under the aegis of the National Center for Health Statistics
4. The Pregnancy Risk Assessment and Monitoring System survey, a project of the Centers for Disease Control and Prevention and some state health departments in which women who recently gave birth are surveyed by mail

Some of the characteristics of direct relevance to indicator measurement arise from an examination of these data sources. These characteristics include the following:

- Data quality, or accuracy
- Cost of obtaining and processing the data
- Frequency with which data are available
- Inclusion of special populations
- Ability to obtain reliable data for sub-national areas and small population groups
- Feasibility of adding or changing data items
- Whether data are collected and made available in ways that allow recombining or tabulating the information in new ways
- Linkages or restrictions of the data to clients of service programs
- Training and supervision of individuals collecting the data, and whether these individuals have a stake in the information yielded by the data
- Value of self-report approaches for eliciting attitudes and behaviors and concerns about the accuracy of such data

This list, though long, is not exhaustive. It is essential, however, to take into account characteristics such as these when indicators are being considered for use.

Quality of Data

What is the quality of the different data sources being used or considered for each indicator? In addition to the measurement issues of data quality, such as validity and reliability, what quality issues are raised by the level of coverage or reporting for different data sources? Is coverage complete, or are only selected populations included? What is the level of nonresponse for different data items, and do those levels indicate that biases may be present in the data?

Relevancy of Data

How relevant are the data for small areas or subpopulations of interest? Sometimes trade-offs must be made between data collected nationally from a single source—and therefore collected consistently across areas—and data that can be used to measure indicators at a local level.

Constructing indicators for small areas or populations raises two potential problems. The first is the problem of obtaining numbers of respondents that are large enough to make reliable estimates. Approaches to doing so include oversampling small groups and merging data from multiple years in order to obtain stable measures. In some cases, groups receiving special focus may be too small to measure reliably in standard ways, and more targeted approaches may be needed. Consideration of approaches for meeting such challenges should be part of the plans of the Reproductive Health Indicators project.

The second problem with constructing indicators for many focused populations concerns the need to identify and obtain the participation of a representative sample of the members of that population. For example, a population may be so widely dispersed that it is very costly to find them. In other cases, the focus may be placed on a group that may be reluctant to self-identify to researchers. For example, many women responding to surveys, especially in face-to-face interviews, conceal the fact that they have had induced abortions. Other characteristics that appear to be sensitive include number of sexual partners, history of STDs, and sexual orientation. As a result, measures for these characteristics, even when available, may be biased because they include only those individuals who are willing to report them. Similarly, "convenience samples" (see Glossary), such as surveillance statistics of STD rates among commercial sex workers, may not be good proxies for rates in the general population.

Technological innovations can help to improve the accuracy of reporting for sensitive topics. One innovation is confidential audio computer-assisted self-interviewing, in which respondents listen to taped questions or read them on a computer screen and enter their answers directly into the computer. Case payments to respondents in the 1995 National Survey of Family Growth improved the response rates for black, Hispanic, and low-income women above those in prior surveys in which such incentives were not used.

IMPLEMENTATION ISSUES

Specifying, measuring, and using reproductive health indicators requires the cooperation of many different individuals, programs, and levels of government. Careful implementation, consultation, and openness in the process will be crucial to the success of this project. In some cases, the data for an indicator must be obtained from service providers, many of whom are

already overburdened by the data collection requirements of different funders and interested organizations. Coordination between funders and oversight organizations can decrease duplication of data and indicators, making data collection and indicator use more efficient and increasing communication and cooperation across organizations.

The way in which indicators will be used is directly relevant to the quality of data that are gathered by stakeholders, such as service providers. These individuals are likely to be more motivated to collect full and high-quality information if they see that the resulting indicator will provide them with useful feedback and direction in achieving their program goals. However, if indicators become directly linked to program funding levels, there may be incentives to pay less attention to collecting information that may be detrimental to the program. Thus, the way in which indicators will be used must be clarified in the early stages, and stakeholders should be involved in these decisions.

Information gathering and access is often decentralized, and individuals must be appropriately protected when their personal data are used. For these reasons, a number of practical steps are necessary to ensure that data are collected and available for indicator measurement. To be successful, all areas of implementation require financial and staffing resources from a variety of mechanisms. The decision-making process by which indicators are selected should include the identification of required and available funding and staff. Careful consideration should be given to what levels and numbers of indicators are possible given the available resources and whether adequate resources can be generated over time to ensure a credible and ongoing process.

Areas that will require focused consideration and resources include clearance, approval, and/or support by potential partners; operationalizing selected indicators, some of which can be simply calculated from available data and others that require new or revised data collection tools; dissemination of indicators; quality improvement strategies; and indicator testing, revision, and additions.

Clearance, Approval, and Support

Clearance, approval, and/or support of the indicators initiative and process is needed from prospective national partners and data-gathering organizations. Agreement, support, and active participation from multiple sources and organizations are essential to propel this effort forward. For this reason, it will be crucial to develop a step-by-step process for review and comment from the very beginning of indicator specification and development. Consideration should be given not only to what that process will be, but also to how it can promote wide acceptance and ownership of the Reproductive Health Indicators Project.

An early and major policy decision is to identify the essential partners who will be needed to approve the indicators. These essential partners should be identified and recruited to participate in the process. Partners who may provide useful input and support, and whose approval may be needed, include appropriate state affiliate organizations, national health organizations, relevant national service organizations, and national expert organizations.

Official review, clearance, and approval, as well as participation and support in the development stage, is likely to be needed from appropriate federal agencies; the Office of Management and Budget; the Institutional Review Boards of provider institutions, states and data collection agencies; and professional, provider, and consumer organizations. Parental consent may be needed to collect certain data on minors, and specific consent may be necessary for gathering information on third parties, such as partners of respondents. Specific consent from individuals may be needed not only to collect data but also to use this information for specific purposes (e.g., biomarker information or blood testing). Some information can be collected without informed consent, whereas some may be gathered with informed consent that is not specific as to its use, and still other information will require that informed consent to specific analyses be obtained.

Operationalization

Selection of indicators should take into consideration the extent to which the various groups involved can contribute to the process, supply data, and use the resulting indicators. It may be necessary to make choices between the breadth of the indicators and the depth of any single one. In this regard, it will be useful to create different classes of indicators according to their readiness for use. For example, it may be wisest to begin with a small set of indicators and to supplement this set with other classes of indicators, such as recommended measures, developmental (pilot or potential) indicators, and others that spring from stakeholders themselves. Some optional indicators could be developed for use by states or other entities according to the indicators' relevance to their situations.

Guidance will be needed in the specifics of defining indicators and selecting the methods to be used in calculating them. Priority should be given to clear and specific definitions that lead to ready measurement. Recommended or acceptable methods for measurement should be defined and illustrated, as should indications of what to do and how to document deviations from the recommended methods when it is not feasible to use them. Although incomparability across areas, populations, or programs should be avoided, it can be useful to know when, how, and why measures deviate from the recommended measurement in order to determine whether they can be compared. It may also be useful to provide software programs that accurately generate indicators from common databases. The use of such programs can improve comparability as well as efficiency.

Guidance on data collection and indicator calculation should be prepared for each indicator. Complete documentation will be needed by the organizations in collecting, reporting, and using indicators. Guidance should be tailored to the barriers and issues that are specific to each indicator but should also be standardized to permit easy use.

Careful consideration will be needed to determine the best mechanism for generating indicators, whether this is by a national organization for all entities, by state organizations for their respective entities, by a variety of organizations or entities, or by mixed methods of generation. Although more centralized generation of indicators may help maintain comparability, organizations that are closer to actual data collection may be more able to understand the specifics of data quality and applicability to their areas.

Dissemination

The dissemination of the indicators is an important step in the implementation process. The various options that are available include a complete national annual document that reports standard indicators for all or some entities, which could be published in print form or as a Web-based report; a national annual benchmark report documenting standard indicators that can be used by entities for comparison; and individual reports for specific programs, regions, or states.

Quality Improvement

Plans for quality maintenance and improvement should be built into the implementation process from the very beginning. The organizations and individuals responsible for collecting and reporting indicators should have training in indicator measurement and reporting. A major policy decision must be made as to the level and type of training that can be provided, specifically, whether enough training can be provided to meet essential needs or whether training requirements will necessitate slower phasing-in of indicators. Because the use of these indicators is essential to the success of the Reproductive Health Indicators Project, training is also needed in using the indicators, especially for those individuals who will be using them for policy, planning, or program decision making. Initial as well as ongoing training for states and other entities and individuals could include formal guidance, training manuals, Web-based training, national or regional workshops, or other mechanisms.

Mechanisms to provide ongoing technical assistance should be available for those who are generating and using the indicators. For example, resource centers could be provided to answer questions, provide consultation, update and revise documentation, generate software programs, maintain a resource library, provide documentation and publications, and provide on-site technical assistance.

Assessment, Testing, and Revision

The development of indicators is not a one-time endeavor. Iterative assessment and improvement mechanisms should be built into the Reproductive Health Indicators Project to provide systematic review and discussion of published and reported indicators. Feedback mechanisms should be used to provide training and assistance. Ongoing support of the project, as well as the continued quality and use of the indicators, can be maintained by providing incentives that reward high-quality reporting and by creating mechanisms for ongoing technical assistance.

Although it may be tempting to move aggressively into implementing the indicators and to move from using established indicators to developing new ones, the experience of others in this area has shown that slower, more considered timetables are needed. Schedules should be developed for testing the feasibility, accuracy, and utility of potential indicators, for reviewing and revising indicators in ongoing use, and for developing additional indicators.

All indicators should be subjected to pilot testing before acceptance. Adequate time should be permitted to implement new indicators, using quality improvement mechanisms during the testing process. Criteria must be developed to determine when an indicator is ready to move

from pilot testing to regular use and when indicators should be discarded or reworked. All accepted indicators should continue to be tested on all dimensions to ensure their ongoing appropriateness when they are implemented on a large-scale basis.

Timely and appropriate mechanisms should be developed to add, modify, or delete indicators on the basis of testing and policy needs. A known process should be in place for periodically including new indicators and modifying or deleting old ones so that those producing and using the indicators can adequately prepare for changes with adequate lead time. They should also be alerted in advance when some indicators come into question or are under study. Those implementing this process should realize that there is a limit to the number of indicators that can be effectively implemented and used, so that when some are added, others are deleted. It may be useful to define a basic, continuing set of indicators and to plan for a rotation of other indicators.

RECOMMENDATIONS

Many of the recommendations regarding scientific, technical, and implementation issues that must be addressed in the Reproductive Health Indicators Project are quite specific. Some general recommendations flow from these considerations, however, including the following:

- Focus the national effort, at least initially, on outcome or status indicators rather than on process indicators.
- Involve a wide spectrum of experts, stakeholders, and consumers in operationalizing the concept of reproductive health into a number of potential indicators. Service providers and those who will be asked to provide data should be involved from the beginning.
- Identify and introduce different classes of indicators, such as basic measures, pilot or developmental indicators, and optional or rotating indicators.
- Allocate enough resources and time to ensure that indicators are measured in valid, accurate, and comparable ways across time, areas, and populations.
- Encourage the use of indicators as program goals rather than as justification for withholding resources.
- As much as possible, capitalize on using existing data and indicators rather than duplicating efforts.

CHAPTER 4:

PROGRAM AND INTERAGENCY CONSISTENCY

In selecting reproductive health indicators, the consistency of those indicators with other indicators currently being used by the Title X program and other agencies must be considered in order to minimize confusion and the added work that will be necessary at the state and local levels to produce the indicators. In this chapter, *consistency* is defined in terms of the selection of reproductive health indicators, and the importance of consistency and barriers to achieving consistency is discussed. The remainder of the chapter focuses on a strategy to promote consistency in developing the definitions of the reproductive health indicators that are ultimately selected.

BACKGROUND

By definition, when things are consistent, they are "in agreement; compatible; conforming to the same principles or course of action; uniform."[1] In the selection of reproductive health indicators, efforts must be made to ensure that the definitions for those indicators are in agreement, or compatible, with the same indicators used by Title X programs and other agencies. More specifically, reproductive health indicators must have numerators and denominators that are defined in the same way and that are derived from the same data sources. For example, indicators from various agencies must have numerators that are all derived from the same source and denominators that are all derived from the same source, although the source for the numerators may be different from that for the denominators.

RATIONALE FOR CONSISTENCY

It is important for reproductive health indicators to be consistent within and among programs and agencies because this provides comparable data that can be compared across programs, agencies, and geographic areas, as well as over time. Consistency can lead to improved quality of care when comparisons can be made between service delivery sites or programs. Having consistent indicators within programs and with other agencies lends credibility to the indicators, because they are considered to be important by more than one group. Consistency can also potentially reduce the workload for those producing the indicators if they are doing so for more than one group. Finally, consistency reduces the time and effort of those developing the indicators, making the process as efficient as possible.

Although consistency is important, it can be difficult to achieve. Moreover, there may be instances in the selection of indicators when inconsistency is actually necessary, such as in the following examples:

- Different denominators would be required for different target populations.

- A definition that is currently used in the field may be inadequate or inappropriate for use in the Reproductive Health Indicators Project. An example is the use of levels I, II, and III to define the hospital of delivery for very-low-birth-weight babies, because these levels are not defined consistently by states. Further, there might be measurement problems associated with the definition, as is the case with "unintended pregnancy." For example, if unintended pregnancy were defined according to data from the Pregnancy Risk Assessment and Monitoring System (PRAMS), this definition would apply to only those pregnancies ending in a live birth. Using PRAMS data for unintended pregnancy in conjunction with abortion data would provide a quite different estimate of the overall scope of the problem..
- Laws or regulations may differ across geographic areas, leading to differences in reporting or definitions. For example, abortion reporting or definitions of marital status or fetal deaths may vary across geographic areas, affecting reporting or how the definitions are formed. In addition, differences in regulations concerning parental consent may cause inconsistencies in data obtained from health surveys on children and adolescents.
- The availability of data sources can vary across geographic areas. For example, data on unintended pregnancies may be measured by using PRAMS data in some states and the Behavioral Risk Factor Surveillance System in others.

STRATEGY TO PROMOTE CONSISTENCY

This section outlines the steps necessary to assess the work that has been done thus far in defining reproductive health indicators, to minimize inconsistency with this work, and to handle the necessary inconsistencies in the definitions that are ultimately developed. The first step is to assess and evaluate previous projects on indicator development at the international, national, multistate region, or state level. Sets of reproductive health indicators developed by other agencies and organizations should be identified that address the key concepts of reproductive health identified in Chapter 1. Several such sets of indicators have already been identified (see Appendix A), but this list will need to be reviewed and updated.

For each indicator set, the following information should be documented:

- Agency or organization leading the development
- Year in which indicators were finalized, how long they have been used, and whether they are still in use
- Breadth of the effort (i.e., international, national, multistate region, or state)

By using the above information, a database can be developed at the indicator level of all reproductive health indicators already defined. This process should start with the *Healthy People 2010*[2] indicators, proceed with other national and international indicator sets, and then move to the multistate and state levels, as time permits.

For each indicator, the database should include the following:

- Name

- Breakdown or subcategories of analysis (e.g., age, race and ethnicity, income level)
- Definition, including data sources for the numerators and denominators
- Lead agency
- Year finalized
- Years in use
- Still in use (yes or no)
- Breadth of effort (international, national, multistate, state)
- Target population(s)
- Portion of the conceptual model addressed
- Use(s) or proposed use(s) (e.g., billing, reporting requirement, monitoring, performance measure, needs assessment measure, provision of comparable data)

Examples of indicators that have been coded in this way are presented in Tables 4–1 and 4–2.

TABLE 4–1. Sample Coding for Indicator: Intendedness of Pregnancy[2]

Name:	Percentage of Pregnancies That Are Intended (births wanted at the time of conception, births occurring later than the time wanted, and births to mothers who didn't care when they occurred)[3]
Breakdown:	• Age (15–44, 15–19, 20–24, 25–29, 30–34, 35–39, 40–44 years) • Race/ethnicity (black or African American, white, Hispanic or Latino) • Income level (poor, near poor, middle/high income)
Definition[3]:	[Number of intended births] divided by [number of live births + abortions in the survey population] x 100
Data source, numerator:	NSFG, CDC, NCHS
Data source, denominator:	• NSFG, National Vital Statistics System, CDC, NCHS • National Survey of Abortion Providers, Alan Guttmacher Institute • Abortion Surveillance Data, CDC, NCCDPHP[3]
Lead agency:	Healthy People 2010
Year finalized:	2000
Number of years in use:	Use of definition just beginning for 2010 objectives; before 2010 objectives, this was stated in terms of "unintended" pregnancies
Still in use:	Yes
Breadth:	National
Target population:	Women ages 15–44
Conceptual model:	Reproductive Health Status
Use:	Monitoring

Abbreviations: NSFG = National Survey of Family Growth; CDC = Centers for Disease Control and Prevention; NCHS = National Center for Health Statistics; NCCDPHP = National Center for Chronic Disease Prevention and Health Promotion.

TABLE 4–2. Sample Coding for Indicator: Percentage of Unintended Pregnancy (Wanted Later or Never Wanted) Among Women Having Live Births

Name:	Percentage of Unintended Pregnancies Among Women Having a Live Birth
Breakdown:	Age (19 and younger, 20–29, 30 and older)
Definition[3]:	[Unintended pregnancy weighted sums] divided by [total weighted sums] x 100
Data source, numerator:	PRAMS
Data source, denominator:	PRAMS
Lead agency:	RNDMU
Year finalized:	1993
Number of years in use:	6
Still in use:	Yes
Breadth:	Multistate region (AL, FL, GA, KY,* MS, NC, SC, TN*)
Target population:	Women ages 15–44
Conceptual model:	Reproductive Health Status
Use:	Monitoring, planning, and evaluation

* These states do not currently have PRAMS.
Abbreviations: PRAMS = Pregnancy Risk Assessment Monitoring System; RNDMU = Region IV Network for Data Management and Utilization.

The second step of the strategy is to identify and minimize inconsistencies once the indicators are decided upon from the conceptual model. Several scenarios come into play at this point.

When there are multiple acceptable ways of specifying an indicator, a table should be produced that summarizes the definitions used by the breadth of the effort. Information in the cells should include the lead agency, data sources, the use or proposed use, and any notes about the geographical levels for which the indicator can be produced. If more than one agency or organization has specified the indicator, all definitions and agencies or organizations should be indicated. Once all definitions have been identified, the appropriate definition can be selected by using the following guidelines:

- Emphasize definitions that have consistently been used by multiple agencies or organizations (including using consistent data sources for the numerators and denominators) and at multiple levels (breadth).
- When consistency is not found, emphasize definitions that have been developed by projects with the greatest breadth; those that can be estimated at the smallest geographical level; and/or those being used as reporting requirements, performance or needs assessment measures, or monitoring measures.

Tables 4–3 and 4–4 provide preliminary examples for how this process might work for two indicators, "Intendedness of Pregnancy" and "Timing of Pregnancy." In the example shown in Table 4–3, the definition specified in the *Healthy People 2010* objectives might be selected for use, but the data set recommended might be that of PRAMS. State-level estimates are possible by using PRAMS data, but PRAMS is available only in 24 states and New York City. It should also be noted that state-level estimates obtained from the Behavioral Risk Factor Surveillance System would not be comparable with those from PRAMS because of differences in the populations sampled.

TABLE 4–3. Intendedness of Pregnancy

Definition	National/international	Multistate	State
Percentage of pregnancies that were unintended	Healthy People 2010 from NSFG Use: monitoring (state-level estimates not possible)		
Percentage of live births that were unintended (unwanted or mistimed)		RNDMU from PRAMS Use: monitoring (state-level estimates possible, but not in all states	TN (future) from BRFSS Use: monitoring (state-level estimates possible, but not in all states

Abbreviations: NSFG = National Survey of Family Growth; RNDMU = Region IV Network for Data Management and Utilization; PRAMS = Pregnancy Risk Assessment Monitoring System; BRFSS = Behavioral Risk Factor Surveillance System.

In the example shown in Table 4–4, the definition chosen might be the *Healthy People 2010* definition, but the data source recommended would be the live birth record, owing to the availability of state-level and sub–state-level calculations.

TABLE 4–4. Timing of Pregnancy

Definition	National/international	Multistate	State
Percentage of births occurring within 24 months of previous birth	Healthy People 2010 from NSFG Use: monitoring (state-level estimates not possible)		
Percentage of live births (excluding first pregnancies) with interval to conception _6 months		RNDMU from live birth records Use: monitoring	

Abbreviations: NSFG = National Survey of Family Growth; RNDMU = Region IV Network for Data Management and Utilization.

In some instances, there may be indicators that have been specified in a way that is thought to be inappropriate, even if the definition is used consistently by others. In these instances, the indicator should not be included if there is another indicator that measures a similar portion of the model and that has been defined previously in a consistent and acceptable manner. If there are no other indicators that measure the desired aspect of the model, the indicator should be defined as it fits the needs of the Reproductive Health Indicators Project, even though this may be inconsistent with previously used definitions.

The last step in the strategy is to identify a process for handling necessary inconsistencies. Although this is not an easy task, one approach would be to form an Interagency Data Workgroup made up of representatives of agencies or organizations, at least at the national level, that are developing reproductive health indicators or are involved in collecting the data needed to produce these indicators. Although not meant to be a complete list, the following agencies and organizations should be considered for inclusion in this group:

- Alan Guttmacher Institute
- Division of Reproductive Health, Centers for Disease Control and Prevention
- Family Planning Councils of America
- State family planning administrators
- Health Care Financing Administration
- Maternal and Child Health Bureau, Health Resources and Services Administration
- National Center for Health Statistics, Centers for Disease Control and Prevention
- National Committee for Quality Assurance
- National Family Planning and Reproductive Health Association
- Office of Women's Health

The Reproductive Health Indicators project group should review the list of proposed indicators and their definitions to determine whether they can agree on ways to produce consistent definitions across these agencies or organizations. If agreement cannot be reached, this

group should acknowledge the need for inconsistent definitions. When the list of indicators is released, it is critical that the Interagency Data Workgroup has reviewed the list with definitions and added an explanation when they feel that inconsistent definitions need to be recommended.

CHAPTER 5:

HIGH-NEED, UNDERSERVED, AND UNDERREPRESENTED POPULATIONS

The purpose of this chapter is twofold: first, to suggest guidelines for ensuring that a full diversity of individuals is represented among populations sampled for monitoring of reproductive health; and second, to consider specific indicators for diverse groups, even if the importance of these indicators is not evident for the entire population.

Public health practitioners know intuitively that some populations have greater needs than others, owing to poor reproductive health status and limited access to health services. Numerous groups are known to be at increased risk for illness, death, and adverse reproductive outcomes. Examples of these groups include young adolescents, homeless persons, HIV-positive individuals, survivors of physical and sexual abuse, families living in severe poverty, victims of racism and discrimination, and workers subject to toxic exposures. Increased medical needs arise from social and economic vulnerabilities and a range of exposures in the physical and social environment, as well as multigenerational genetic, biological, and environmental legacies. Establishing priorities for the effective public health monitoring of persons with such vulnerabilities and exposures is a challenging and important task.

The terminology used throughout this chapter evolved out of a close critique of the often-used labels "special" and "high risk." The titles or names applied to specific groups required thoughtful consideration because the intent here is to challenge rather than reinforce the stigmatization and exclusion of subpopulations. For this reason, the term *special populations* was rejected. Persons or groups may require special attention because of their environments or the ways in which they have been treated, not necessarily because of their individual behaviors or anything that is innately "special" about them. It was decided to avoid the term *special populations* because it might mistakenly place the onus of health problems on individuals rather than pointing to deficiencies in health systems or to forms of social discrimination.

Persons labeled as "high risk" tend to be stigmatized once classified as such, and solutions to individuals' problems are sometimes impeded by this characterization. As Handwerker[1] suggests, "labeling poor pregnant women 'high risk' implicitly and explicitly makes them accountable if they are unable to change their behavior as prescribed by medical professionals" (p. 665). Despite the subjective, arbitrary, and sometimes prejudicial nature of medical risk assessment, Handwerker[1] notes that, during her ethnographic fieldwork in a public prenatal clinic, she "never observed a 'high risk' label being removed from a patient, regardless of any improvement in the designated risk factor or behavior (e.g., drug use)" (p. 669). Another suggested term, *priority populations*, was rejected because it implied a ranking of groups according to their needs or problems, which is inappropriate.

The choice of the terms *high-need*, *underserved*, and *underrepresented* refers to specific concepts that are consistent with this chapter's mission to address the need for affirmative attention, specific strategies, and possibly differential allocation of resources for groups with demonstrated health vulnerabilities, problems, or access barriers. The need for particular focus

on such groups could be fluid or transitory, because group definitions reflect a set of circumstances and not necessarily inherent or persistent characteristics of persons or populations. The term *high-need* was selected because it is descriptive and suggests the importance of context rather than the permanence or inevitability of disparate need. *Underserved* is meant to refer to both the quantity and the quality of health care that is accessible, acceptable, and free of stigma or bias. The term *underrepresented* was chosen because monitoring of community representation is considered essential in health care settings among staff, advisory committees, and boards of directors, as well as patient populations.

Given resource limitations, it is essential to understand and redress health disparities that may be masked without close monitoring of potential inequalities. Existing reproductive health indicators for the general population are extremely limited, and development of indicators for subpopulations is in its infancy. In establishing national reproductive health indicators for the first time, pragmatic concerns will dictate a short list of leading indicators for initial implementation. For the long-term effectiveness of this important project, it will be equally important for criteria to be set forth clearly from the outset for the future development of more extensive and inclusive indicators. Ongoing opportunities should be developed for government agencies, researchers, providers, and local communities to identify new indicators that become relevant and significant.

BACKGROUND

The US Department of Health and Human Services' *Healthy People 2010*[2] targets the elimination, not merely the reduction, of health disparities. Rather than naming "special populations" for targeted monitoring and tailored objectives, as was done in previous versions, *Healthy People 2010* establishes the goal of eliminating disparities among sociodemographic groups. In most cases, the objective for each subgroup is to exceed the performance of the group that currently has the most advantageous indicator; for example, if a particular racial or ethnic group has the lowest rate of pregnancy complications in the baseline data, that group *and all others* should improve on that rate by 2010. This method of setting goals is referred to as "Better than the Best" in the *Healthy People 2010* documents. The new approach not only avoids setting lower expectations for groups with lower benchmarks, but also sets goals for all groups to improve and to reach parity.

Healthy People 2010 focuses on differentials occurring by gender, race or ethnicity, and socioeconomic status as measured by education or income. For some *Healthy People 2010* objectives, disparities are considered according to age, disability status, urban or rural residence, and health insurance status. Certain *Healthy People 2010* objectives designate populations with specific medical conditions, such as diabetes, hypertension, and arthritis.

Because group comparisons are only as meaningful as the groups' definitions and measurements allow, decisions about classification of population groups are critical. Recent changes in the Office of Management and Budget's Directive 15 on racial and ethnic classification (i.e., the subdivision of the Asian/Pacific Islander population into the two subcategories of "Asian" and "Native Hawaiian and Other Pacific Islander") and changes in

terminology, as well as the decision to allow self-identification in more than one "racial" category, raise challenging questions of data validity, reliability, and consistency over time. Currently available measures for evaluating socioeconomic status and racism are extremely limited but increasingly important to measure social inequalities and discrimination.

Principles

For the purposes of this chapter, a set of principles has been agreed upon for the selection and measurement of reproductive health indicators for high-need populations. These principles are described in the following paragraphs.

The first of these principles states: "Optimal reproductive health and elimination of disparities should apply to all populations and to all individuals within those populations." An "optimal" standard should be stressed as a positive goal. The intention underlying this principle is not only to raise the population group mean to a level that is "better than the best," but also to ensure equity within as well as between groups. Equity in itself does not guarantee universal and continuing improvement. Ultimately, indicators of wellness, well-being, and quality of life will be needed to assess whether optimal health has been reached.

The second principle is: "Priority must be given to disparities in health between the general population and high-need populations, and appropriate and adequate resources must be made available to eliminate those disparities." This principle places major emphasis on the importance of resource allocation and addressing disparities in services and resources (versus differences among populations themselves). It may be necessary to provide positive incentives to redress disparities. Because the persistence of institutional racism penetrates and reproduces power structures within health care delivery systems, equalization of resources may not be sufficient.[3–5] Under current policies, and given market pressures, providers are actually penalized financially for serving populations that require additional resources. Such policies and pressures lead to patient disincentives for utilizing care, reduce access for high-need populations, and exacerbate health disparities. Allocation of resources, including support for community-based education and mobilization, should be given strong emphasis here.

The third principle is: "The entire process of developing a reproductive health indicators selection framework must incorporate the concept of cultural competency." "Cultural competency" should not be interpreted as a purely linguistic issue lest ineffective and tokenistic means are employed to conform to this principle. Therefore, other key aspects of cultural competency were defined, including measures taken to eliminate discrimination and to ensure an inclusive and welcoming environment. Appropriate education and training are required to ensure that staff in public and private agencies make diverse populations feel welcome, not only by speaking their languages but also by respecting their cultures and developing the ability to interact with people of different cultures. Important elements include understanding gender as well as cultural beliefs and values and treating all patients with dignity. Although health agencies cannot transform every aspect of their patients' environments, it is important for health personnel to be aware of the ways in which members of underrepresented groups may experience insults to their health and well-being in workplaces and neighborhoods.

Addressing Racism

There is a need to challenge and uproot the entrenched racism directed toward historically underserved groups while taking preventive measures to protect newly emerging and expanding groups that may face discrimination. Larger groups that have been present in communities for a long time must not be overlooked in efforts to combat discrimination and eliminate disparities. A strong sentiment was expressed that such groups may become "invisible" to policy makers and that long-term disparities tend to be accepted as the status quo, obscuring the need to direct resources to populations who have suffered the greatest and most persistent disparities.

Because resource issues are systemic and underlie racism, it is essential for strategies to be inclusive. Pitting one high-need population against another in competition for resources is destructive to all and must be avoided. In order to change power imbalances, there must be representation and leadership by those who have suffered historically and who currently experience institutional racism in all forums of discussion and decision-making related to health services planning, policy, and resource allocation. Recommendations must address the impact of institutionalized racism on health care delivery.

The principles laid out in this chapter should be incorporated into the Reproductive Health Indicators Project's conceptual framework and infused throughout the working model and resulting recommendations. Concerns about racism and discrimination, inclusiveness, and genuine cultural competency must be addressed at each step of the process of developing reproductive health indicators. Sensitivity to gender issues and inclusion of men are other cross-cutting issues that should inform future indicators.

ESTABLISHING GUIDELINES

Criteria

The workgroup reviewed the Centers for Disease Control and Prevention's Guidelines for Evaluating Surveillance Systems,[6] which were published in 1988 and are currently undergoing reevaluation. As "parameters for measuring the importance of a health event—and, therefore, the surveillance system with which it is monitored,"[3] the CDC guidelines provide a structure for considering issues related to indicators for high-need populations. These guidelines are considered in the following paragraphs.

Total number of cases, incidence, and prevalence is the first of the guidelines proposed by the Centers for Disease Control and Prevention (CDC). Although even one case may represent a sentinel event that signals a severe problem or inequity, in general the total number of cases for small population groups may not be a useful criterion for determining the importance of the condition or event. Incidence and prevalence estimates provide better comparability between population groups of different sizes. Definition or classification of high-need groups is important in this respect because low incidence or prevalence for the entire population may mask the extent of problems in high-need populations.

One concern expressed in the workgroup was the trade-off involved in aggregation of groups. On the one hand, large numbers allow for greater statistical significance, social mobilization, and maximum impact of interventions. On the other hand, "lumping" of dissimilar groups threatens the loss of specific information, especially for small groups. The task was not seen as a focus on "minority" populations, because the vulnerability of groups might be independent of their size and the totality of vulnerable groups might compose a numerical majority of the total population. Another concern was that emerging needs of newly identified groups should not be overlooked; however, resources spread too thinly could dilute the necessary focus on historically underserved (and possibly larger) populations.

Indices of severity, such as case/fatality ratio, and *mortality rate* are the next points raised in the CDC guidelines. Because maternal mortality is a rare event in the United States, the case/fatality ratio may not be a very sensitive measure of reproductive morbidity. Because severity tends to be measured by the use of health services, serious morbidity may be differentially underreported among groups with limited access to care. In addition, systemic and provider bias may deter the detection and documentation of disease chronicity, disability, discomfort, and dissatisfaction among underserved populations.

Indices of lost productivity (e.g., bed-disability days) may need to be measured in different ways for women than is done with the standard methods designed for men, in order to account for women's interrupted patterns of participation in the labor force and uncompensated caretaking responsibilities. An *index of premature mortality*, such as years of potential life lost, may be more appropriate, although women's life expectancy varies with membership in more or less advantaged populations.

Medical cost is another measure that is dependent on access to and utilization of care. Charges must be standardized if used as a proxy for morbidity, because publicly financed care may be reimbursed at a lower rate than privately insured treatment.

Preventability of conditions seems to be a useful criterion for monitoring of high-need, underserved populations. However, standard measures of preventability are defined by available modes of medical treatment and utilization of health services, exclusive of important factors such as freedom from discrimination, respect for women, cultural competence, and other aspects of quality of care. The workgroup raised some interesting questions specific to monitoring the preventability of adverse reproductive health outcomes. For example, how does unmet need for family planning services factor into preventability of reproductive health conditions? Since the critical outcomes of optimal reproductive health include healthy offspring, which conditions among infants and children should be considered preventable with optimal reproductive health of the mothers? These are but two examples of the complexity associated with determining preventability in relation to reproductive health indicators.

Strategies

More questions than answers resulted from discussions of strategy, because strategic directions will be determined in the next phase of the Office of Population Affairs' Reproductive

Health Indicators Project. The workgroup reached a basic agreement that guidelines for high-need, underserved, and underrepresented populations should fall into two categories.

The first of these categories is adequate inclusion of such populations in data collection for national reproductive health indicators that are established for the whole population. Because in many cases this will be difficult or impossible to achieve with existing sources of data, the following issues should be taken into consideration:

- What strategies are needed for the inclusion of populations with small aggregate numbers or sparse populations that are broadly dispersed? Is there a lower limit on the size of a population that can be monitored meaningfully and reliably?
- What enhancements to routinely collected national data (e.g., vital statistics, surveys, administrative data) could improve the ability to monitor subpopulations?
- How should the relative importance of national, state, and local data be weighted?
- What types of data collection efforts in smaller geographic areas, small area analysis, alternative sampling strategies, systems of sentinel event or sentinel site surveillance, and periodic or special studies should be considered?

The second category is the development of specific indicators relevant to particular high-need, underserved, or disenfranchised groups. For example, homeless women or women with HIV/AIDS might face unique reproductive health risks. It would not be efficient or necessary to monitor the entire population for such risks, but it might be unethical to ignore the potential for certain conditions among specific groups. Areas of discussion for guidelines in this second category should include the following:

- Which populations or subpopulations are likely to have unique risks and to need unique indicators?
- How can denominators be determined for monitoring of such populations?

RECOMMENDATIONS

Defining Populations

Starting with the population categories used in *Healthy People 2010* (e.g., gender, age, race and ethnicity, disability status), the workgroup added other categories and suggested numerous subgroups that might be included under each category. The list below is not meant to be exhaustive nor the categories mutually exclusive; classifications are not fixed and are not meant to imply any system of ranking. The group's approach was to try to achieve inclusivity and to enumerate groups that might require focused monitoring regardless of the current availability or quality of data. A watchword of the group's effort was that data can always be collapsed into larger categories but cannot be disaggregated without adequate attention to detail in data collection.

The workgroup's goal was to suggest general guidelines and to provide thought-provoking examples in order to move the project forward with respect to reproductive health indicators for

high-need populations. Optimal coverage of high-need populations should be explored as fully as possible before feasibility is assessed. At that point, priorities will clearly need to be established. A "laundry list" approach is unrealistic for a national monitoring system; one danger of such an approach is the risk of diluting concern for major population groups whose needs have been historically ignored. However, consideration of a broad range of populations will allow for variations in local monitoring and attention to timely problems that arise in national, state, or local settings. A commitment will be needed to continue searching for resources to achieve adequate coverage of all groups that warrant concern.

Gender. Prior efforts to monitor reproductive health have been inadequate and have tended to focus primarily on infant outcomes, neglecting many important aspects of women's health. Men constitute an underserved group for reproductive health services and have not been a focus of reproductive health surveillance. The lack of access by men to family planning services; the lack of education, screening, and treatment of men for reproductive risks, including occupational exposures; and the failure to address the needs of men as fathers through public policy have negative consequences for women and families as well as for men themselves.

Age. Potential age categories for monitoring reproductive health should include the entire life course, specifically, women less than 15 or greater than 44 years of age (even though they are not included in *Healthy People 2010* family planning objectives, and women >35 are all aggregated into one group in *Healthy People 2010* maternal health indicators). Attention should be paid to adolescents in foster care and those who have dropped out of school as potentially high-need groups.

Race and Ethnicity. Conformity with federal reporting classifications mandated by the Office of Management and Budget's Directive 15 should be maintained when appropriate for purposes of consistency and comparability. Within and beyond the standard categories, specific ethnic or national subgroups should be delineated whenever this is feasible, important for local needs, and relevant for purposes of improving public health. One suggestion was to create a larger "Cultural" category that would subsume subcategories of race and ethnicity.

Socioeconomic Status and Quality of Life. Improved measures of socioeconomic status, including but extending beyond education and income, are critically needed, and the interaction of socioeconomic status with all the other categories is extremely important in assessing high need. Specific populations of concern are individuals who are homeless or inadequately housed, such as those living in substandard, transitional, or public housing; and persons who are hungry, malnourished, have insufficient food, or lack food security.

Immigrant Status. Service needs and access to health care may differ among documented and undocumented immigrants and migrant workers. National origin, length of time in the United States, legal status, citizenship, and degree of acculturation may also be relevant factors.

Disability Status and Morbidity. It was generally agreed that a "Disabilities Status" category should include persons with physical disabilities, severe and persistent mental illness, or mental retardation or other developmental disabilities. Consensus was more difficult to reach concerning the classification of persons with non-permanently disabling illnesses. One

suggestion was to classify illnesses as disabilities and divide them into subcategories as acute or chronic, but this was controversial because persons with various illnesses do not necessarily consider themselves as having disabilities. Women with poor underlying health status need to be identified for preventive measures to improve reproductive health. Women experiencing the sequelae of childbirth and inadequate follow-up care, such as uterine prolapse, pelvic support disorders, and incontinence, might be considered among those with chronic illness or, alternatively, as a population with age-related concerns.

Stigmatizing Medical and Behavioral Risks. Women living with certain medical conditions (e.g., HIV/AIDS and other sexually transmitted diseases) and those with substance use disorders face health risks that may be aggravated by stigmatization and legal complications.

Sexual Orientation. Categories of persons that should be considered high-need populations include lesbians and gays, women who have sex with women but identify themselves as heterosexual, men who have sex with men but identify themselves as heterosexual, bisexuals, and transgendered persons.

Residence. Rural, urban, and suburban residence may be associated with particular needs concerning environmental exposures, access to health and other services, and confidentiality.

Institutionalization Status. Institutionalized persons in need of focused attention may include those who are (or have been) incarcerated in the criminal justice system or institutionalized due to physical and/or mental disabilities. This category includes residents of nursing homes.

Abuse. Women who are being or who have been physically, sexually, and/or psychologically abused are definitely a high-need group for reproductive health monitoring.

Women in Hiding. Women who live in hiding, due to immigration status, abuse, and/or substance use leading to fear of deportation, arrest, violence, or loss of child custody, lack access to health care and health promotion activities.

Cultural and Religious Minorities. It was suggested that certain religious and cultural groups might require focused attention because of objections to health service utilization or particular interventions such as immunization or family planning. Practices or behaviors based on these beliefs may have an impact on the health of the general population as well as the specific group.

Policy-Sensitive Conditions. Populations might be identified due to their vulnerability to changes in federal or state policies. These include women who become ineligible for welfare due to time limits or other new regulations.

Program Eligibility. Populations may be defined by eligibility for financing or service programs, such as Indian Health Service and Title X programs.

Environmental Exposures. Workers in hazardous occupations or industries, such as sex workers, workers exposed to radiation and toxic chemicals, and agricultural workers, face specific reproductive risks. A category overlapping with residence is exposure to hazards in the physical environments where people live and work.

Ethics. Women who participate in research related to reproductive health, receive experimental treatments, or serve as subjects in clinical trials for other treatments that might affect their reproductive health are subject to ethical concerns that require monitoring. Similar concerns apply to women receiving assisted reproductive technologies, even after such technologies receive approval from the Food and Drug Administration or professional bodies.

Genetics. Concerns related to persons with genetic susceptibilities become more relevant as genetic information proliferates and genetic screening increases. The potential for new treatments is great because genetic risks can be identified more easily, but the risks of stigmatization, discriminatory treatment, and coercion in reproductive decision-making must be monitored.

Other Considerations

Multiple Risks. Underserved individuals may have multiple characteristics that raise concerns for reproductive health. It may be useful to construct an index of need or to define a constellation of risks that are likely to coincide. It should be possible to do this without recreating the problems associated with the "high-risk" label.

Group Members. High-need, underserved, and underrepresented groups are heterogenous, and membership in such groups may be a transitory condition for individuals. It should therefore be determined what is the importance of individual-level data, including longitudinal linked data, versus ecological or aggregate population-level data and cross-sectional analyses. In addition, it should be determined how we can allow for fluidity in group membership and identity and what we can learn from variation within subgroups.

Local Representation. An ongoing process will be essential to obtain continuous input from representatives of groups being monitored. As social conditions, policies, and health care delivery systems evolve and change, members of designated populations should play an important role in developing data collection strategies. Community representatives should be involved in formulating recommendations for future monitoring to provide information that can be used at state and local levels.

CONCLUSION

These and many other unresolved questions remain for future stages of the Reproductive Health Indicators Project. The workgroup on High-Need, Underserved, and Underrepresented Populations appreciates the opportunity that the Office of Population Affairs has provided for serious discussion, diverse national input, and genuine consensus building around important and deeply felt issues.

CHAPTER 6:

ETHICS AND SERVICE QUALITY

This chapter addresses the intersection of ethics, service quality, and reproductive health indicators. The ethical domain encompasses principles and procedures that ground all research processes, including those involving the development and implementation of reproductive health measures. The quality section focuses on some of the factors beyond family planning that are used to assess health care. Suggestions are also provided for addressing service quality within reproductive health.

Next, the intersection of ethics, service quality, and reproductive health indicators is presented. Although it is often acknowledged that these factors are highly interrelated, many of the issues reflected by ethical concerns within service delivery or the impact of measuring clinical services on quality of care have received limited attention within the field of reproductive health. This is a tall order of work and one that goes well beyond this brief chapter. Some topics can be only outlined here and await fuller treatment during the next stage in the development of reproductive health indicators. Others will simply be acknowledged as long-term projects.

Finally, the workgroup members believe strongly that there are broad concerns in these substantive areas that cannot (and should not) reach closure, in part because it would contravene the ongoing process to identify and address ethics in health research and practice. Given this perspective, the material presented here should raise more questions to be engaged than answers in which we might take false comfort.

BACKGROUND: RESEARCH ETHICS

Sound ethical principles and procedures are necessary conditions for research on human subjects. This statement requires that three terms be defined. First, *ethics* is the study of problems of right conduct in light of moral principles, in which the goal is to provide guidance on what to do and how to treat others.[1] Second, *research* refers to any systematic investigation designed to contribute to generalizable knowledge. Importantly, for policy purposes this definition includes the array of tasks identified in prior chapters for developing, testing, and evaluating reproductive health indicators, regardless of whether these activities are supported under a program identified as "research." Third, *human subjects* are living individuals about whom research practitioners obtain 1) information through interaction (either directly or via a third party) or 2) identifiable private data.[2]

Concerns about research ethics were not systematically addressed until the mid-20th century. Historic benchmarks demarcating this effort have included the Nuremburg Code (1946), the National Institutes of Health's initial federal policies for protection of human subjects (1953), the World Health Organization's Declaration of Helsinki (1964) and the Belmont Report (1979).[3] More recently, research ethics within reproductive health have been examined at international

conferences, specifically, the International Conference on Population and Development (ICPD) (1994) and International Planned Parenthood Federation (1995). The ICPD is noteworthy in its efforts to define reproductive health and to situate relevant health issues within a larger ethical context. At this event, a consensus document was developed that 1) defined reproductive health, 2) set priorities concerning human sexuality and gender relations, 3) linked reproductive health to larger socioeconomic and political issues (e.g., development in Third World nations), and 4) acknowledged the far-reaching impacts of sexually transmitted diseases (STDs) and HIV/AIDS prevention on women's overall health.[4]

The Belmont Report and Research Ethics

Although the documents and meetings just mentioned are all concerned with ethics and reproductive health indicators, the Belmont Report is perhaps most central to national policy development and practice guidelines.[5] It therefore may be useful to describe the principles described in this report and their implementation via statute and federal program.

Three basic ethical principles were identified in the Belmont Report as apposite to research involving human subjects: 1) respect of persons, 2) beneficence, and 3) justice.

Respect of persons implies two components: 1) acknowledging individual autonomy and 2) protecting those with diminished capacities. The consequence of this principle and its requirements is that subjects participate in research activities voluntarily and with sufficient information to make an independent determination about their involvement. The practical result is the implementation of informed consent procedures. The second component, protection of those with diminished capacities, may be a function of age, illness, mental disability, or circumstances (e.g., prisoners in correctional facilities). Decisions about sampling and informed consent among those with diminished autonomy often present dilemmas to research activities.

Beneficence, the second Belmont principle, is an obligation to 1) do no harm and 2) maximize possible benefits and minimize risks. This can be a particularly challenging principle to assess in practice. Obviously, estimating "risk" involves not only research subjects but others associated with that individual (e.g., immediate family members, sex partners) as well as weighing risk and reward across various time frames. On a more general level, there is the need to weigh research's overall benefit to society against an individual's risks of participation in a particular project.

Finally, the third Belmont principle, justice, refers to a sense of fairness and equal treatment. As a research issue, this principle focuses on just methods to distribute burdens and benefits to subjects. This principle is often reflected in project sampling procedures, such as decisions about sampling frames, elements, and strategies. Justice is also relevant when the end results of research are addressed. Public support for data collection activities should lead to improved service, treatment, or technology without regard for who can afford to obtain access to these benefits.

Applying these three ethical principles results in the following research requirements:

1. Informed consent
2. Risk/benefit assessment
3. Fair procedures for selection of subjects

These requirements are codified in statute. Title 45 of the Code of Federal Regulations, Part 46, "Protection of Human Subjects," provides a framework under which research efforts must be assessed. The Department of Health and Human Services (DHHS) Office for Human Research Protections manages compliance with these regulations for all DHHS-funded research. In practice, this is accomplished through a complex set of individuals and agencies (e.g., Institutional Review Boards [IRBs]) reviewing proposed and ongoing research activities and making judgments about human subject procedures and protections.[6]

Ethics, Review Processes, and Reproductive Health Indicators

In the preceding section, a fairly straight line is drawn from ethical first principles to their codification and then the process by which these criteria are applied to research activities. Unfortunately, this simple schema leaves out many concerns that make the real implementation of ethical guidelines so difficult. There are a broad set of issues that should caution us against underestimating the problems inherent in addressing ethics and the development and implementation of reproductive health indicators.

A first concern is with language—terms and definitions—and how they fit within our historical context. The ethical principles enumerated earlier are maddeningly vague and complex concepts. For example, "beneficence" as an edict to do no harm leads to a welter of cross-currents when trying to define "harm" and "risk" to individuals, groups, and communities. It also may be all too easy to view this discussion atomistically, without recognizing historical or community and national views toward reproductive health. An approach that is limited to trying to determine an individual's risk as an autonomous agent ignores a real history of conflicts concerning women's self-determination and ability to act to minimize risk and maximize benefits.

A second problem involves the sometimes uncomfortable fit between research and its oversight via IRBs. Despite the broad definition of "research" used in statute, IRBs routinely distinguish between various types of scientific endeavors relating to indicators. Moreover, the way in which a project is labeled—as research, program evaluation, or routine data monitoring—can determine whether an IRB will decide that the activity should be reviewed. Significant variability can occur among local IRBs when determining whether a reproductive health indicator project falls under their purview. IRBs have many challenges in defining their roles and reach in their local scientific communities. The types of research (clinical trials, population surveys, psychological experiments, ethnographic studies, etc.), IRB members' views and understanding of key ethical terms, and the community's history in addressing research risks and rewards all play a role in decisions about what activities come under their jurisdiction and how stringently a project is examined.

A third concern involves tying this issue of ethics and research too closely and simply to IRBs. Although IRBs play a central role in overseeing research or research-like activities, other governmental agencies and statutes also have jurisdiction over such projects. For example, the Office of Management and Budget and the Food and Drug Administration have additional oversight procedures and practices. At the other end of the governmental spectrum, many cities and counties maintain offices that provide guidance or monitoring of data-related activities without recourse to standing IRBs.

These general points should lead to an important conclusion for guiding the OPA's next steps: Some systematic process must be identified to rigorously assess the ethical dimensions of a reproductive health indicator project. This process may or may not include IRBs, other governmental agencies or offices, advisory groups of scientists and citizens, and so forth. The larger question is not "Does the project have an IRB?" but rather "Have project activities been adequately examined and monitored in relation to ethical principles?"

SERVICE QUALITY IN REPRODUCTIVE HEALTH CARE

The second major area addressed in this chapter is quality in reproductive health care. The workgroup's initial task was to clarify what is meant by *quality*. Two distinct topics were identified: quality of health indicators and quality of health care service implementation. The former, however, actually falls under the purview of the Scientific and Technical Issues workgroup (see Chapter 3). The "quality" concern within this chapter is closer to client services and staff performance—the conditions under which services are implemented and assessed and the possible effect of indicator systems on service delivery.

Quality is closely tied to both ethics and indicators. Ethics is a necessary context that is strongly associated with all processes identified in measuring reproductive health. This measurement process may inform as well as affect service quality and patient outcomes, which in turn may be monitored with further assessment of reproductive health indicators. Ethics have been understood in the health professions as more than the systematic examination of morality. Rather, it is now understood as a responsibility to provide quality health services. This practical approach to defining ethics is reflected in health care associations maintaining codes of ethics for professional practice and quality service delivery, whether this is clinical service, management, or ancillary (e.g., laboratory) activities.[7]

Recent efforts have intensified in assessing quality of health care service delivery. The Health Care Quality Improvement Act (1986), for example, was focused on promoting professional practice review and improving quality of care. In addition, a wide array of practical theory-based systems have been developed to assess and monitor quality across public and private systems.[8,9] Beyond legislation and interventions, public program guidelines also address—at least globally—service quality. A relevant example of the latter is the Title X guidelines concerning levels of care for defining clients and medical visit events.[10] However, the workgroup members judged that quality improvement in reproductive health service delivery lacks a coherent system-wide approach. This in no way minimizes the efforts noted above but rather highlights some of the challenges reflected in Chapter 1. The scope and depth of services

and how they are provided in the United States, as well as the politics associated with family planning, women's health, STDs and HIV, and sexuality, all add to the challenge of assessing the quality of reproductive health care.

Despite these concerns, health professionals have systematically implemented assessment of health care quality, particularly in the last 10 years.[11] These efforts have often addressed the ethical issues inherent in quality measurement. They have also maintained a focus on the practical consequences for systems, organizations, practitioners, and consumers of health care services. Through this process, a few points stand out. First, measuring quality is important. It can lead to changes in health services. Second, where measurement has been standardized, it is possible to assess variability in service quality. Third, the technical difficulties in measuring quality cannot be overestimated. This entire document is a testament to the complexity of issues that must be addressed to begin the process of generating valid and reliable measures of reproductive health services and outcomes. Fourth, the quality improvement field clearly recognizes that technical developments in measurement may affect the level and distribution of resources Finally, there is growing recognition that defining and measuring quality can have unintended consequences on the health care service delivery system.[12]

As work continues on devising reproductive health indicators, two related quality issues should be addressed. The first is recognition of the various system components where quality can be assessed. The second involves examining possible standards for selecting measures of quality. For the former, evaluation of quality can be based on structure, process, or outcome.[12] Examples of structural elements are the background and training of staff, agency capacity, technology and equipment, community service access, and even funding. The process component for reproductive health quality is particularly critical and centers on encounters between personnel and patients. This encompasses the complexities of each individual's views of the experience as well as documentation of procedures and short-term outputs. Finally, outcome measurement entails identifying and monitoring patients' subsequent reproductive health status. In addition to these challenges, it is clear that structure, process, and outcome evaluation can be conceptualized at the individual or aggregate levels.

Many different research approaches can be taken when attempting to measure the quality of system structures, processes, and outcomes. Research and evaluation activities in the health and behavioral fields have ranged from rigorous case-control studies to more descriptive quantitative methods to qualitative exploratory studies. Examples of data sources include patient records, surveys, interviews, focus groups, structured observations, and routine surveillance systems, to name just a few. The point here is not to provide a listing of every type of data source or research design but rather to emphasize the complexity inherent in attempts to capture quality in reproductive health care. This complexity is a function of content areas, evaluation focus (structure, process, outcome), measurement criteria, and methods or data sources.

The second quality issue that must be addressed involves the standards for selecting measures. Significant work has been done in the field of reproductive health to generate valid and reliable measures, particularly for national "snapshots" of women and family planning needs (see earlier chapters). However, this present effort can also build on work done in other health care systems that have grappled with codifying assessment activities. Specifically, the National

Committee for Quality Assurance (NCQA) has been a leader in improving the quality of health care provided through managed care plans. Of particular interest is their work on performance measurement, which has been undertaken with a wide array of partners and collaborators from the public and private sectors. The primary tool used in this effort is the Health Plan Employer Data and Information Set (HEDIS), which is a set of standardized measures used to describe and compare health plans.

In developing HEDIS, NCQA identified three general attributes for their measures of health care systems.[13] Measures would be assessed on their relevance, scientific soundness, and feasibility. Each of these criteria includes numerous subcategories on which to assess potential quality measures. For example, relevance components cite the extent to which measures are meaningful, important to the nation's health, financially significant, and strategically important. In addition, they should address cost issues and should be amenable to control or change. Measurement criteria for scientific soundness cited by NCQA are the availability of clinical evidence, reproducibility, validity, and accuracy. Other technical concerns with scientific soundness are the extent to which the measures are affected by factors beyond the control of the health care system, the extent to which measures vary across health systems, and incompatibilities between data sources. Feasibility criteria for potential reproductive health indicators might include the specificity of operational definitions, data sources, collection methods and costs, reporting, confidentiality, and audit procedures.

The above criteria set comprehensive and rigorous standards for measuring private health plans. A public sector measurement tool, Medicaid HEDIS, has also been devised on the basis of these criteria. However, those working in this area of assessing health plans warn against blindly adopting these attributes when grappling with other measurement projects. The NCQA standards focused on measures that are applicable to comparing health care systems. They may not be appropriate for tracking quality improvement or comparing health care at different levels of aggregation (e.g., among patients or between clinics, states, etc.).

Risks and Rewards of Quality Measurement

Explicating risks and rewards must be a critical component of any program addressing the development of indicators and a system for their collection and use. Philosophic as well as strategic reasons exist for monitoring risks and rewards. The ethical concern acknowledges that measuring is not an end in itself. Rather, it should be a means for attaining some goal, such as increasing the efficacy of public sector health care delivery or improving the nation's health. The strategic or practical concern is that maintaining measurement systems over time requires collaboration among stakeholders, researchers, practitioners, and patients. Failures in collaboration and monitoring may leave a newly developed system open to potential problems with maintaining its support and implementation. The following paragraphs provide examples of the possible risks and rewards of measuring quality. It is by no means an exhaustive list but should provide an initial context for some of the issues that could be assessed during the development and institutionalization of a reproductive health indicator system.

Risks

Some risks in measuring quality are reactive. In this case, the measurement system is perceived as a response to some implicit or intended change in policy or practice. Under this scenario, quality measurement might be viewed as instrumentally serving ends that are inconsistent with the system's goals. For example, measuring quality has caused concern among some health care advocates as a smoke screen for funding cutbacks. In an outcomes-driven world, failing to document positive results may provide justification for reallocating resources. Another related risk is that quality measurement is a reaction to funders shifting to interventions with readily quantifiable results. This concern makes no judgment about the outcome's importance, only that some dependent variables are more amenable to data collection.

A second set of risks associated with quality measurement focuses on the intended or unintended consequences of the process. In this case, the risks are the results of measuring client services, system access, or other indicators. For example, the demand for documented results could drive programs away from their historic mission. There is a concern that "simply" measuring certain behaviors or conditions may slowly shift an agency's or service system's focus in terms of clients or activities. A related risk is the concern that, in order to meet benchmarks for measurable outcomes, an agency might shift its efforts away from improving conditions for harder-to-serve clients. This risk in quality measurement clearly intersects with ethical concerns for ensuring fairness in, for example, selecting research subjects or doing outreach to potential program clients.

Finally, there is a clinical service risk when operationalizing quality in situations where the measurement process might lead to services deviating from professional standards for best practice. For example, when characterizing family planning outcomes, data on a woman's pregnancy status could be augmented with information on her attitudes and intentions as well as her partner's perspective. Focusing measures solely on the health condition, such as pregnancy status or "couple-years" of protection, might inadvertently result in services that minimize individual decision making over time (e.g., shifting to higher use of injectable contraceptives). This may or may not be consistent with other clinical guidance centered on the client's plans to determine the number and spacing of her children. This example highlights a concern best stated by one workgroup member that an indicator system could result in staff "studying to the test." Decisions about what is measured can affect what participants do.

Rewards

Many of the potential rewards of a reproductive health indicator system are the optimistic counterpart of the issues raised above. Summary information that is carefully measured, collected, and analyzed can clarify the connections between a system's or program's mission and its actual results. A further practical implication is informing participants (e.g., managers, front-line staff, and policy makers) about progress toward a goal and highlighting possible directions for future efforts. Both of these rewards could be strong motivators for system stakeholders who are trying to balance "big picture" issues of policy direction, disease trends, and so forth, with the daily details of health care service implementation. Reproductive health indicator data can be a powerful link between these two worlds that energizes those engaged in reproductive health,

family planning, and STD/HIV prevention. Even when reproductive health indicator systems identify, for example, gaps in services to a particular population or the enduring nature of some social and health problems, these data should form the basis for system change, training opportunities, technical assistance, and shifts in research priorities. In this sense, the indicator system provides meaningful guidance for purposive change or critical reexamination of attitudes, beliefs, and practices. Finally, there is a positive side of linking data to decisions about funding. It is possible that funding endures for reasons beyond service quality and efficacy. Incorporating empirical results of indicator systems can, or even should, be a factor in the public processes that lead to difficult decisions in a world with resource constraints.

Intersection of Ethics and Quality with a Reproductive Health Indicator System

Describing the intersection of ethics and quality with a reproductive health indicator system may reprise points made earlier in this chapter. In doing so, the workgroup identified three cautions about the possible efficacy of this process.

First, articulating explicit ethical principles to guide the development, maintenance, and use of reproductive health indicators does not guarantee protection of individuals. Although obvious, this skepticism concerning the gulf between intention and action deserves to be stated clearly and often.

Second, resources are needed if issues of ethics and quality are to be monitored within a reproductive health indicator system.[14] If it is the case that technical concerns about operationalizing reproductive health services and outcomes cannot be divorced from ethical principles and a critical examination of quality, then funding is required beyond the "scientific" tasks to ensure that these larger connections are examined.

Third, the field of reproductive health in the United States has a limited history of addressing these technical, ethical, and quality concerns when devising indicators. This last point in no way diminishes the hard work of many scientists, policy makers, practitioners, and concerned citizens who have grappled with these issues. It is simply acknowledging that we presently do not have a consistent set of reproductive health measures that are implemented across service delivery systems or the general population and that are applicable at national, state, and local levels.

Regardless of these cautions, the workgroup strongly believed in situating ethical and service quality issues within the development and implementation of a reproductive health indicator system. The brief presentation below summarizes some of the issues raised earlier in this chapter and points to recommendations from this group.

Process for Developing the Indicator System

The earlier stages in the indicator system development process should allow for sufficient engagement with key stakeholders. Ideally, the new system will be strengthened by involving participants and partners in setting goals, prioritizing constructs, identifying safe and secure data collection procedures, and developing oversight procedures for unanticipated consequences or reviewing potential changes to the process. All of these project activities are consistent with

ethical concerns and a focus on monitoring service quality. This process would balance the technical deliberations expressed in earlier chapters with ensuring fair representation of the broader issues in reproductive health, including measurement of the full array of family planning and STD services to all client constituencies, including, for example, adolescents, low-income families, racial and ethnic minorities, and persons with disabilities.

Once the inclusive aspects of the start-up process have been emphasized—in terms of both the participants and the project's scope—ethical and quality concerns might be brought to bear on the feasibility of data collection. Here, too, the emphasis must be placed on asking questions about data collection within a public service sector in which multiple funders require different measures (or similar items with different operationalizations). The workgroup did not view ethical and quality issues as "deal breakers" that would doom implementation. Rather, they recognized that their concerns for a practical data project were truly consistent with scientific design issues to ensure accurate and consistent data.

The last ethical and quality concern during start-up might focus on the end uses of the data collection system. It is reasonable to assume that key stakeholders would have some clear expectations. Specifically, data collected on service delivery (as distinct from national descriptive information) should not be used to assign "pass/fail" grades to programs. This is particularly the case for systems engaged in innovative approaches to access and service delivery, such as OPA's male involvement and outcome projects. Additionally, approaches to examining the data, as well as the forms or layout for disseminating results, should be outlined in advance. This would allow for critical study of the congruence between agreed-upon goals for the indicator system with the proposed structures for describing the results. Finally, basic ground rules should also be developed during the initial project phase about disseminating indicator data and results. As a related issue, guidelines also must be generated for data access and publishing.

Implementation of the Indicator System

The ethics and quality issues of maintaining an indicator system are distinctly different from those just considered during the initial project phase. Two sets of implementation concerns are summarized in the following paragraphs, under the general headings of "Time" and "Structure." The first set of concerns has to do with some of the ethical and service quality issues that arise in the management of an indicator system over extended periods of routine implementation. The second set of concerns has to do with examination of the concerns raised in this chapter across federal, state, and local levels, or how ethics and quality are conveyed "vertically."

Time. Three temporal issues are outlined here in relation to implementing a reproductive health indicator system: 1) changes in policy, 2) program funding constraints, and 3) maintaining system integrity. Changes in policy and statutes should be monitored in relation to indicator measurement and service quality. Ideally, data elements should be routinely reviewed to ensure their usefulness in relation to shifting public health priorities. Conversely, the results from the indicator system would ideally play a role in debates about changing health policy and legislation. The ethical issues raised above concerning whose voices and views are included during start-up are also relevant here. The reproductive health indicator system requires an explicit and equitable process for reviewing changes in measures and their implementation.

The second temporal issue is more concrete. Title X family planning programs routinely address funding constraints over time that may have ethical and service quality implications. Workgroup participants noted that local agencies (with multiple funding streams) have sometimes expended their allotted Title X funds before the end of the fiscal year. This problem raises ethical questions about equitable and fair service delivery. Service outputs (e.g., contraceptives provided) may vary based on the month when clients show up for appointments. This systematic variation may also raise problems about measuring public sector results and service quality to inform future system needs.

Perhaps the most challenging temporal aspect of ethics, quality, and indicator measurement is maintaining rigor and consistency during system implementation. The technical side of this issue has been raised in other chapters. Here, the concern rests on the implications of this challenge. Unplanned changes in how data elements are understood and captured affects summary measures of service need and use. These changes should be controlled as well as possible through training and system monitoring in order to minimize errors of all types. There also is a converse to decisions about rigor: it is important to actually implement the system so that new information is part of future discussions about service quality, while acknowledging that rigor is a developmental process. In terms of implementing systems, one workgroup member succinctly noted: "Don't let the 'perfect' get in the way of the 'good.'"

A related issue concerning consistency and rigor involves generating and using data systems over time. For example, some data collection efforts may attempt to capture confidential information at multiple time points from system clients or individuals. The challenges and needed safeguards inherent in such efforts are significant.[15] Alternatively, other measurement systems routinely capture client events or characteristics without the added rigor of unique identifiers. In this case, questions of ethics and quality, though different, remain important. For example, in recent years, some "family planning" and "STD" clinics have reorganized as "reproductive health" sites. Monitoring client characteristics, disease burden, contraceptive use patterns, and other elements over time must be examined critically when assessing service mix, quality, and access, given the possible changes in the populations served or the agency's mission.

Structure. This section briefly raises ethics and quality issues involving indicator implementation across system levels (i.e., local, state, regional and national perspectives). Data security is a major ethical concern across structures. Some indicators may involve confidential data collection, such as capturing client or citizen names or sufficient numeric fields that technically could allow a determination of who was interviewed or surveyed. Confidential data may be particularly useful in that they allow either tracking changes in client status or condition over time or provide the possibility of linking information across systems. These more complex data activities can significantly improve assessment of quality services and their efficacy. They also raise ethical issues in terms of procedures to ensure subjects' privacy, particularly when data sets are transferred from local to state or federal agencies.[16] In some cases, there may be inconsistencies between the data needs of local, state, or federal agencies and program guidelines, state laws, or federal regulations. These insconsistencies or conflicts might be particularly challenging with highly sensitive health information, such as STD case reporting, HIV test results, or pregnancy outcome data. However, even in reproductive health arenas where

somewhat less sensitive measures (e.g., client demographics) are accurate and available across levels, data transfer and security must be examined and each level's concerns resolved satisfactorily.

A second structural issue is service funding across local, state, and federal levels. Here, numerous ethical and quality concerns are related to reproductive health indicators. For example, in assessing indicators for program efficacy, there may be significant variation in blending of funds within systems at the state or local level. Title X is often only one source of dollars in service delivery systems. An assessment of Title X quality and the ethics of comparing system outcomes must take into account this fiscal reality. In addition, variations in service provision must be considered by funding source. A Title X client may be eligible for different clinical services than the patient sitting next to her in the waiting room who is covered by private insurance.

The complexities of funding and its relationship to reproductive health indicators should not obscure an even simpler ethical and quality issue that was posed during the workgroup's deliberations: What are the funding requirements for meeting the reproductive health needs of clients in publicly supported programs? Developing indicators, particularly for program efficacy and client outcomes, should involve a critical examination of both historical and projected funding for government programs. For example, are the levels of and changes in funding a factor in determining the mix of services and contraceptive options provided to poor women seeking reproductive health care? During start-up of the indicator system, how does one set benchmarks for quality service and outcomes that take into account variation among states and localities in total funding for reproductive health for Title X programs as well as other resources? What are the moral questions in choosing indicators, given the range of decisions made concerning service delivery, client outreach, and resource allocation?

These issues have ramifications even for recent initiatives within Title X. For example, OPA has recently set a goal of increasing the number of clients served under Title X. There are technical challenges in measuring additional patients. In addition, however, what are the implications for best practices if prioritizing new clients affects follow-up services and continuing clients' access to return visits?

Finally, routine data systems are an integral part of health care service systems. Maintaining a reproductive health indicator system may rely in part on existing program information systems. To the extent that this occurs, there is a need to understand the strengths and weaknesses of these ancillary data sets across structures. For example, STD surveillance systems are based on local reporting to state or city health departments. Variation in local coverage as well as in technical capacity will affect summary measures generated at the state or regional levels. In addition, the use of these confidential data records in conjunction with other health service information can raise ethical concerns. For example, in some public health localities, family planning and STD clinic data systems may be merging as services are consolidated. Although this may improve our understanding of client populations, it would also require resolving possible conflicts about confidentiality and sharing local information with state systems.

A slightly different issue arises for special program initiatives. OPA supports pilot projects across the country addressing service innovation and client outcomes. Ideally, a common set of measures and data collection protocols could be implemented to ensure consistent, high-quality information. However, family planning outcome work may not be far enough along, particularly in relation to the concern for improving service access to high-risk populations, to warrant a set of common multisite evaluation procedures. This realistic limitation may affect the utility of these data for informing reproductive health status among this set of projects as well as for broader program guidance.

RECOMMENDATIONS

Summary recommendations to OPA are presented below for ethical and quality issues within a reproductive health indicator system. The first set of recommendations refers to system development; the second set concerns ongoing implementation.

Indicator System Development Process

- Provide a draft of the indicator project's Request for Proposal (RFP) to representatives from each workgroup. Feedback from this dissemination process should be part of OPA's development of the published RFP.
- Create an ad hoc committee to work with the contractor selected from the RFP process.
- Identify and recruit representatives from other government agencies, professional associations, and stakeholder groups with expertise in examining ethical and quality service issues to participate as committee members.
- Clarify policies for relevant OPA-funded outcome projects concerning human subjects review procedures. This may be particularly appropriate for demonstration programs that include evaluation components rather than explicit "research" endeavors.
- Begin a process (similar to NCQA's efforts) of determining the desirable attributes of reproductive health indicators.

Indicator System Implementation

- Ensure the development of a plan for addressing human subjects protection issues in the indicator system project. Incorporate relevant elements of this plan in all technical documents and presentations concerning the implementation stage.
- Oversee identification of the administrative unit(s) responsible for ensuring human subjects protection in the project.
- Examine the possibility of incorporating data elements from the indicator system as core measures in other OPA-funded research and demonstration projects, such as Service Delivery Improvement (SDI) grants and special initiatives such as male involvement. (The focus here is not on the technical usefulness of this approach, but rather on minimizing risks to and burdens on subjects concerning data collection.)
- Develop guidelines for the use and sharing of indicator system data. Plan for strategic partnerships with other programs engaged in related health and human service indicator systems.

- Include project activities to evaluate the impact of collecting reproductive health indicator data on key system elements, such as service quality for patients, partners of patients, service providers, and reproductive health service system change (e.g., policies, service mix, and reimbursements).

CHAPTER 7:

CONSIDERATIONS FOR TITLE X FAMILY PLANNING PROGRAMS

This chapter presents a case study in which the principles and concepts presented in Chapters 1 through 6 are applied to the federally funded Title X Family Planning Program. The Title X Program is one of several publicly funded programs, such as prenatal, sexually transmitted disease, and HIV programs, that should have active representation in the development of a national reproductive health indicators set.

BACKGROUND

In 1970, the US Congress passed Title X of the Public Health Service Act, creating a national family planning program. This legislation established a federal funding base for public and private nonprofit organizations to provide "educational, comprehensive medical, and social services necessary to aid individuals to determine freely the number and spacing of their children."[1] Within the federal government, the Title X Program is administered by the Office of Population Affairs (OPA) in the Office of Public Health and Science of the Department of Health and Human Services (DHHS).

Title X family planning services are available to all persons in the United States; priority is given to low-income individuals. According to the fiscal year 2002 funding request to the Office of Public Health and Science, more than 4.4 million individuals received family planning services from a network of more than 4,600 clinics supported by the Title X–funded Family Planning Program in 1998, the last year for which data are available. This service system is managed primarily by state health departments and regional nonprofit family planning councils that are the recipients of Title X grants.

In addition to this vast network of clinical service providers, the Title X Family Planning Program also mandates and provides funding for public information and education addressing family planning and population growth, training for service providers, and research related to family planning and population issues. Because of its national scope, the Title X Program needs to be strongly aligned with the reproductive health indicators that are selected for this national project. Such an alignment will create a visible presence for the Title X Program and will establish its role in contributing to the overall reproductive health and well-being of individuals living in the United States.

The workgroup on Title X Applicability recommends that, within the context of the Reproductive Health Indicators Project, OPA adopt a set of performance indicators for the Title X Family Planning Program that address the multiple mandates of Title X legislation. These indicators should provide a basis for broad public education about the importance of family planning and the purpose of the national family planning program. Title X Program indicators should relate both conceptually and pragmatically to the national indicators that are selected as a result of the Reproductive Health Indicators Project.

This chapter highlights the themes underlying this recommendation, discusses the issues that are central to the development of a Title X Family Planning Program indicator set, and presents considerations for moving this activity to the next phase. Issues covered in this chapter may raise more questions than they answer because the initial phase of the Reproductive Health Indicators Project has launched an important effort that is in need of continued work. Therefore, the final section of this chapter contains a set of recommended future actions.

OVERVIEW OF THEMES

Conceptual Framework

A national set of reproductive health indicators should include both population and program measures in order to provide the fullest vision and definition of reproductive health status and health care in the United States. The proposed conceptual framework described in Chapter 2 is suitable for embracing a set of indicators applicable to the Title X Family Planning Program. In addition to population-based factors, this model includes program-based factors such as those relevant to the Title X Program. Although the Title X Program, with its network of providers, cannot take responsibility for a set of population-based outcomes, it can be accountable for and report on programmatic measures that contribute to population-based outcomes. Therefore, it is important for the Reproductive Health Indicators Project to adopt a model that creates a clear connection between program and population measures. Such a connection will serve to educate the general public and policy makers about the value of program services to the reproductive health status of the population. In this model, program services can emanate not only from the Title X network but from a host of other providers and funders. These include, but are not limited to, community health centers, state and local health clinics, private practitioners, hospitals, managed care organizations, and insurance carriers. Representatives from these groups should also be actively involved in the planning of the national Reproductive Health Indicators Project.

Aligning Title X with a National Indicator Set

A major challenge in selecting the indicators will be limiting the total number of indicators for national reporting. Because this national set of indicators must be concise in its ability to "tell the story" about reproductive health status in the United States, it cannot possibly represent all the program indicators that would be relevant to the Title X Program. It is therefore suggested that a set of program indicators be developed specifically for the Title X Program. From that set, a designated number of program indicators can be represented in the national set.

The quest for a set of Title X Family Planning Program indicators allows OPA to link with several performance projects that are underway both within the field of family planning and in other related federal agencies. Presently the Family Planning Councils of America, the State Family Planning Administrators, and DHHS Regions IV, VI, VIII, and X are each working on projects to develop performance-based indicators for family planning programs. At the federal level, indicator projects that clearly relate to and include family planning measures are ongoing in the Maternal and Child Health Bureau of the Health Resources and Services Administration

and in the Sexually Transmitted Disease Program Division of the Centers for Disease Control and Prevention. (A listing of these and other indicator projects can be found on the OPA Web site at www.hhs.gov/progorg/opa/titlex/indicators.) In addition to linking with these efforts, Title X Program indicators should also link to *Healthy People 2010*[2] objectives and form a basis for OPA performance reporting, as required under the Government Performance and Results Act (GPRA).

Title X as the Cornerstone for Family Planning Program Indicators

The Reproductive Health Indicators Project affords OPA a unique opportunity to position the Title X Program as the cornerstone for providing comprehensive family planning services in the United States. Not only is the Title X Program broad in its vision and mandates, but it has successfully established an impressive network of service providers with a funding infrastructure that allows these providers to efficiently use funding from other sources to expand on the limited resources provided by Title X. In some areas, state and local revenues add to and complement Title X–funded services. In other areas, Title X providers are successful in obtaining federal or foundation funding to implement enhanced service initiatives and to assist in reaching underserved populations. At times, it has been the Title X Program, with its service standards and funding base, that has aided service providers in staving off local or statewide attempts to dismantle or reduce publicly supported family planning services. The Title X Program has both the stature and the presence of a large and diverse service system to provide leadership in the selection of program indicators that can set standards and define benchmarks for comprehensive family planning services. OPA can use these indicators as a basis to justify annual requests for resources from Congress that are sufficient to meet and maintain service needs. In time, Title X family planning program indicators can and should become a model for other agencies and providers, such as state and local health departments, private practitioners, neighborhood and community health centers, and insurance programs.

Comprehensive Family Planning Services as Defined Within Reproductive Health Care

The broad definition of reproductive health proposed in Chapter 1 implies a vast range of clinical services that outstrip the current funding level of the Title X Program but not necessarily the capacity of the provider network to offer this range of services. In fact, Title X–funded service providers in the Title X Applicability workgroup noted wide variations in the reproductive health services they are able to provide as a result of the resources that are available to them. In examining this definition and the range of services delivered by the Title X family planning provider network, the Title X Applicability workgroup challenged itself to define the scope of services that comprise *comprehensive family planning care* within the reproductive health life cycle of individuals.

Guided by Title X program standards and concepts of service integration, the workgroup began to list and categorize into the following two groups a wide range of reproductive health services:

1. Comprehensive family planning services
2. Related reproductive health services

This list of services is shown in Appendix B and is presented as a suggested draft document, not as a definitive product. This exercise was useful in providing a sense of the range of clinical services that can be represented in a comprehensive family planning indicator set for the Title X Program.

Core and Expanded Indicators

Although Title X may represent an expected standard, not all Title X–funded providers have the resources to offer the full range of services suggested in the comprehensive family planning service package shown in Appendix B. Even fewer of these providers have resources to offer the types of services listed under the "Related Services" category in the Appendix B. It is therefore suggested that the Title X family planning indicator set be comprehensive in scope but conceptualized as having indicators that fall into one of two groups: a core group and an expanded group. The core set would constitute a constellation of services that are given primary focus and funding through the Title X Program. The expectation is that Title X providers will report on these measures because they represent Title X program and funding priorities. At present, not all services listed under comprehensive family planning services in Appendix B would be designated as "core" services, because not all providers have the resources to offer them.

Beyond the core set of indicators, the Title X Applicability workgroup conceptualized an expanded set of family planning indicators, implying that additional resources or expertise are required to deliver the services related to these indicators. These indicators might represent future directions or developmental areas for the Title X Program. They would come from both the Comprehensive Family Planning Services list and the related Reproductive Health Services list shown in Appendix B, as appropriate to Title X legislative mandates. Title X providers would voluntarily elect to report on indicators culled from this expanded set. This flexibility would allow DHHS regions, states, or councils to select standardized indicators that are applicable to their own program initiatives, partnerships, resources, and local community needs. In addition, Title X providers may elect to develop an indicator and report on it as an expanded service component, with technical assistance provided through OPA to develop a standardized measure for the indicator. This aspect would be useful in creating indicators for target populations or services based on local needs. Reporting on expanded indicators would allow OPA to document the extent to which Title X providers are able to leverage Title X funding with other resources in order to accomplish broader program objectives and to offer a wider array of reproductive health services for individuals based on community needs.

Several advantages to designating core and expanded indicators for the Title X Program are evident:

- Family planning indicators would be uniformly defined and measurements standardized, even though they may not be of primary (core) interest at the time.
- Title X providers would have an incentive to expand their programs and would be able to report on these expansion activities.

- Title X providers would have the option to present their own initiatives while remaining accountable for a core set of indicators.
- The framework creates a dynamic system for the selection and reporting of a wide range of Title X Program indicators.

ISSUES SPECIFIC TO A TITLE X PROGRAM INDICATOR SET

Needs and Uses of an Indicator Set for Title X Programs

In both principle and practice, Title X Program indicators should be framed and used in such a way that they promote program progress and improvement. They should not imply absolute standards by which individual programs will be judged as either "passing" or "failing."

The Title X Applicability workgroup identified three primary uses for the Title X Program indicator set:

1. **"Telling the Story"—**There is a need to present a public image of the Title X Program for the purpose of educating and building broader awareness and understanding of both family planning issues and the Title X Program.
2. **Monitoring and managing—**Indicators are valuable for program planning and quality improvement. They help measure progress over time and identify areas where improvements and resources need to be focused.
3. **Strategic planning and goal setting –** Indicators enable programs to set and work toward achieving benchmarks, they ensure the use of common definitions and measures, and they focus programs on working toward common program goals.

Similarly, there are three major audiences for reporting information on indicators. Each of these audiences may find utility in any or all of the uses of indicators as noted above:

1. **Beneficiary audiences—**Audiences such as family planning clients, families, communities, businesses, and the at-large public who are stakeholders in the health and well-being of communities, who want assurances that local needs are being addressed, and who look for accountability of programs at the community level
2. **Internal (or management) audiences—**Audiences such as OPA, DHHS Regional Program Consultants, and Title X service providers who use indicators to measure progress, set and attain goals, and make adjustments to programming on the basis of indicator findings
3. **External (or resource provider) audiences—**Audiences such as legislators, Office of Management and Budget, policy makers, the media, public and private funders, and insurance plans, all of whom are able to influence and/or allocate resources on the basis of indicator reports. These audiences are also capable of ensuring program longevity and furthering the public agenda on reproductive health issues.

Indicators Based on Program Effectiveness

Efforts to establish program effectiveness are useful in establishing a set of program indicators. Family planning programs do not have the resources (or, in some instances, the expertise) to individually demonstrate the effectiveness of their services. However, if indicators are designed to measure program components that have demonstrated effectiveness, this will allow stronger links to be made to population-based outcomes, although these are not directly measured. Members of the Title X Applicability workgroup stressed the importance of being able to link the rationale for program services to improvements in health status. This connection is essential for "telling a compelling story," especially in efforts to secure resources for program services.

For example, theoretical models suggest that the availability and use of emergency contraception has the potential to reduce the incidence of unintended pregnancy (a population-based outcome). Therefore, a program indicator that measures the availability of emergency contraception offered by reproductive health providers can be linked to a desired population-based outcome. However, such linkages between program indicators and population outcomes cannot and should not imply causal relationships. As illustrated by the model presented in Chapter 2, factors other than program factors can intervene and result in either more or less favorable outcomes at the population level. For example, although emergency contraception services may be widely available in a community, individuals may not obtain access to those services as a result of personal beliefs and behaviors.

Reporting on Indicators

In selecting indicators for the Title X Family Planning Program, every effort should be made to minimize the burden of data collection and reporting on Title X service providers. Additional resources may be required by programs in order to collect and report on meaningful data. To the extent possible, existing data sources should be examined for their potential value. In addition to the indicators, OPA should provide standardized definitions and measures to ensure comparability of the information collected, compiled, and reported in indicator format. In instances where the collection of universal data is impractical or prohibitively expensive, OPA may consider establishing sentinel data collection centers that provide representational data for states and regions. These can be weighted and aggregated to produce estimates for reporting on the national program.

Indicators should not be reported in isolation of the programmatic context from which they are derived. An essential aspect of "telling the story" is sharing the meaning and implications of what is reported in the indicators. Indicator findings must be presented within a narrative format that expands on the intent and meaning of the indicator with a particular audience in mind.

Domains for Program Indicators

As mentioned earlier, several indicator projects currently underway are developing family planning program-based measures of performance. OPA should build on the experience of these projects with the goal of adopting relevant aspects of their work rather than duplicating the

effort. The Title X Applicability workgroup examined the conceptual framework of several of these projects and found substantial areas of overlap in the selection of domains. Domains are broad conceptual areas under which specific performance measures are categorized. The considerable overlap in domains selected by these projects provides justification for using them as a basis for the Title X indicator set. Although the work on these indicator projects has occurred independently of the Reproductive Health Indicators Project, it is reassuring to note that these domains are consistent with the selection of domains presented in Chapter 2.

Overlapping domains in these ongoing projects include the following:

- Access to clinical services
- Use and delivery of services
- Cost-efficiency
- Effectiveness and quality of care
- Individualized counseling and education

Domains represented in some but not all of the ongoing projects are as follows:

- Management
- Governance
- Public education
- Provider training
- Client satisfaction
- Community involvement

The differences in the domains selected by these indicator projects appear to be related to the specific objectives of each project. Yet taken together, the projects encompass domains that the Title X Applicability workgroup members view as inclusive of the diversity and breadth of the Title X provider network and its activities. In addition, these domains represent the legislative mandates of Title X ,with the exception of the research mandate, which will need additional consideration as a Title X indicators project moves forward.

ADDITIONAL CONSIDERATIONS

The Title X Applicability workgroup addressed a range of considerations related to the Reproductive Health Indicators Project. Some of these considerations are relevant to the Reproductive Health Indicators Project in general, but most are specific to the selection of family planning program indicators.

FPAR and GPRA

The selection of Title X Family Planning Program indicators should be made in consideration with other reporting requirements. Each year, Title X service providers submit the Family Planning Annual Report (FPAR). This report provides information on family planning service users (by selected demographics and types of services provided). It does not provide

information on users of non-medical services supported by Title X, such as public education and counseling provided in the absence of medical services. It also provides information on family planning providers and on sources of revenue. Although it has its uses, FPAR is fairly limited as an effective management tool and should be revised in light of the Reproductive Health Indicators Project. Under GPRA, OPA is required to submit to the Office of Budget and Management a performance plan for Title X–supported programs and activities. This document links performance measurement to federal budgeting and is a critical step in acquiring resources and justifying Title X funding increases. Clearly, the concept of performance-based program indicators is central to both FPAR and GPRA. Planning and selection of indicators should be done in conjunction with the needs of these reporting systems.

Benefits of Collaboration

Outside of OPA, considerable efforts have been made with respect to performance-based measures in several areas. Already noted is the work by the Family Planning Councils of America, the State Family Planning Administrators, DHHS Regions IV, VI, VIII, and X, the Maternal and Child Health Bureau, and the Centers for Disease Control and Prevention. Together, these efforts comprise a combination of population and program-based indicators that should be studied carefully and integrated into the continued work of the Reproductive Health Indicators Project. In particular, the work on family planning performance indicators already underway (e.g., the Family Planning Councils of America, State Family Planning Administrators, and DHHS Regions IV, VI,VIII, and X) can save time and create efficiencies for OPA in pursuing indicators for the Title X Program. The Title X Applicability workgroup noted the importance of selecting program indicators that are linked to objectives in *Healthy People 2010*. For the purpose of the Reproductive Health Indicators Project, the objectives in *Healthy People 2010* should be viewed as including all the reproductive health focus areas (for example, HIV, sexually transmitted disease, and maternal and child health) and not limited to those in the Family Planning Chapter. *Healthy People 2010* is viewed by the workgroup as an important tool for both the Reproductive Health Indicators Project and Title X Program indicators.

Scope of Program Indicators

By adopting the concepts of core and expanded indicators, the program indicator set for Title X programs will be able to measure change in the capacity of the Title X service network to offer a range of reproductive health services and/or expansion of services to underserved populations. At the same time, the program indicator set will be able to measure the quality of the performance on indicators viewed as "core" to the Title X Program. There should be flexibility and significant service provider input in determining the core and expanded set of indicators for the Title X Program.

Flexibility of Program Indicators

The Title X indicator set will be most useful in setting benchmarks against which progress is measured, not as pass/fail measures of performance. When the indicators are viewed and presented in this manner, there will be wider acceptance among Title X service providers of the utility and importance in reporting on indicators. In addition, the benchmarks and the indicators

themselves need to be viewed as dynamic and capable of being changed and modified on the basis of available resources and policy considerations.

Principles and Ethical Considerations

Once identified, family planning program indicators should be presented within a context that describes fundamental principles and ethics in service delivery. These principles espouse the voluntary and confidential nature of service provision. They speak to informed consent practices and nondirective counseling approaches. They include complete access to accurate information and education about family planning issues, including, but not limited to, all contraceptive methods and pregnancy options. They also address the principle of equal access to quality services regardless of age, income, race or ethnicity, gender, sexual orientation, marital status, citizenship, or physical or mental ability. Quality service implies cultural sensitivity and the provision of counseling, education, informed consent, and printed materials in one's preferred spoken and/or written language. (These issues are dicussed in depth in Chapter 5.)

Focus on Gender, Reducing Health Disparities, and Positive Outcomes

The selection of reproductive health indicators (including those for family planning) should be gender inclusive. Indicators should encompass measures that promote the reproductive wellness of both women and men. Although Title X providers primarily serve females, where resources permit there is a growing trend and willingness among providers to offer family planning services for males. Therefore, services for males should be recognized in the selection of both core and expanded family planning program indicators. Additionally, the indicators should be sensitive enough to measure progress on the elimination of reproductive health disparities among various population groups served by Title X programs. A concerted effort should be made to present all indicators in positive, health-affirming (rather than health-deficient) terms. (These issues are discussed further in Chapter 5.)

Implementation Issues

Once indicators are selected for the Title X Program, they should be piloted in a limited fashion by Title X providers so that the effects of data collection and reporting can be assessed. Several of the indicator projects underway are about to begin pilot phases that can provide instructive experience on implementation issues, such as cost and the feasibility and burden of data collection on providers. Beyond the pilot stage and along with input from the provider network, OPA should set a realistic timeline for implementation and should actively assist providers in meeting the timeline expectations. (Other issues concerning implementation of an indicator program are discussed in Chapter 3.)

Access to Information by Title X Providers and Program Administrators

To be used effectively in planning and management, program indicators must be reported in a timely fashion and accessible to the service provider network and DHHS Regional Program Consultants. Standardized data and reporting systems should be established with sufficient funding to support the development and maintenance of these systems and ensure timeliness and

comparability of the data collected. In most cases, a 12-month reporting cycle will suffice to produce planning-level information, provided that publication of the indicator findings is reviewed and shared promptly with Title X providers and DHHS regional offices. Such timeliness will also benefit program accountability in OPA's reporting requirements under GPRA.

Use of Indicator Reports

Indicators should be selected with a specific and shared purpose in mind. When reported, the intended purpose of each indicator should remain clear and the potential for misrepresentation minimized. Under-performance on indicators should not result in punishment or sanctions for service providers. Rather, program indicators should be used for qualitative improvement, and benchmark settings should be clearly established. Technical assistance should be available to help providers improve their programs performance according to indicator findings. Careful consideration should go into the preparation of written documents or electronic posting of information. It is likely that a single, generic format will not be suitable for all purposes and audiences, as discussed earlier in this chapter. With audience and purpose clearly in mind, each published report (whether in electronic or hard-copy format) should provide a narrative that introduces the purpose of the reported indicators and expands on the findings, thus providing a context in which the intended audience can assimilate the reported information.

RECOMMENDATIONS

The workgroup on Title X Applicability proposes the following as future actions:

- Develop a communications strategy for sharing the results of this phase and future activities of the Reproductive Health Indicators Project with Title X service providers. This strategy should provide for ongoing information sharing and feedback on the time frame and process of selecting Family Planning Program Indicators and their link to the Reproductive Health Indicators Project. This strategy should include how to handle the management of perceptions, facts, and misinformation that might result and interfere with establishing commitment and ownership of the indicators project by the Title X provider network.

- Building on the current Reproductive Health Indicators vision statement, issue a specific vision statement for the national Title X Family Planning Program. The vision should be based on the concepts and issues addressed by the Title X Applicability workgroup.

- If a Request for Proposal is issued and a contractor selected to complete work on the Reproductive Health Indicators Project, the workgroup strongly advises continued and substantive representation in the planning and implementation process from the Title X service network, in addition to representation from other funding agencies, professional organizations, insurers, and individuals with related expertise.

- Continue work toward achieving consensus in defining comprehensive family planning care, as proposed within the spectrum of life span reproductive health services. This work is essential to the selection of program domains and specific indicators within those domains. This effort is also beneficial to defining the scope and quality of activities for which Title X resources are to be used or leveraged in partnership with other federal, state, or local funding streams.

- Further explore the concept of core and expanded indicators, not only with respect to the clinical services component of the Title X Programs (as presented in this chapter), but also with respect to the community education, provider training, and research components of the Title X legislation.

- Move forward with substantive integration of FPAR and GPRA reporting requirements and linkage of these with the *Healthy People 2010* objectives so that these measures can be included with the work on the National Reproductive Health Indicator Project.

APPENDIX A:

SELECTED RESOURCES

Charting a Course for the Future of Women's and Perinatal Health
Volume I: Concepts, Findings, and Recommendations
Volume II: Reviews of Key Issues
Holly Grason, John Hutchins, and Gillian Silver, Editors
Single copies of the two-volume publication are available at no cost from the National Maternal and Child Health Clearinghouse at (703) 356-1964 or by visiting http://www.nmchc.org.

Prepared by the Women's and Children's Health Policy Center at the Johns Hopkins School of Public Health and sponsored by the Maternal and Child Health Bureau/HRSA/DHHS (March 1999), this compendium provides the background and context of the initiative from which the Issues Summaries in Women's and Perinatal Health were derived, recommendations made by experts in the field in addressing these issues, and the full text of the 13 individual issues summaries. All documents produced by the Charting a Course for the Future of Women's and Perinatal Health Initiative were developed to guide future policy and program development, enhance support for advocacy and educational efforts, and assist in program monitoring and evaluation.

Consensus in Region IV: Women and Infant Health Indicators for Planning and Assessment
Regional Network for Data Management and Utilization (RNDMU)
Cecil G. Sheps Center for Health Services Research
University of North Carolina at Chapel Hill
725 Airport Road, Campus Box 7590
Chapel Hill, NC 27599-7490
http://www.shepscenter.unc.edu/DATA/RNDMU
To order a hard copy call (919) 966-5764 or e-mail Janet cortes@unc.edu

Consensus in Region IV: Women and Infant Health Indicators for Planning and Assessment (1998) is the product of a collaborative effort between the Regional Network for Data Management and Utilization and the North Carolina State Center for Health Statistics. Begun in the early 1980s as a Special Project of Regional and National Significance (SPRANS) Maternal and Child Health Bureau, DHHS, the RNDMU project originally targeted its efforts toward helping states in Region IV reduce its high rate of infant mortality. In 1990 the family planning directors, along with the MCH directors and directors of the state health statistical agencies from each of the eight states in Region IV, met with several outside consultants to expand the indicators so that they more completely addressed the planning and evaluation needs of family planning programs. Again, in 1997, the women's health directors met with the family planning and state statistical directors from each state to begin the process of expanding the indicators to look at women's health issues not directly related to their reproductive health. With the 1998 edition of the Consensus document, 17 years of data on many of the indicators are now available; 12 years are summarized on the Internet.

The EVALUATION Project
Carolina Population Center
University of North Carolina at Chapel Hill
CB# 8120 University Square
123 West Franklin Street, Suite 304
Chapel Hill, NC 27516-3997
http://www.cpc.unc.edu/projects/evaluation

The EVALUATION Project is an initiative funded by the US Agency for International Development (USAID) to support technical and methodological advancement of population program evaluation. The project is executed under contact to the Carolina Population Center at the University of North Carolina at Chapel Hill in collaboration with the Futures Group and Tulane University. The purpose of the EVALUATION Project is to strengthen the capacity of USAID and host-country institutions to evaluate the impact of population programs on fertility. The project has produced the *Handbook of Indicators for Family Planning Program Evaluation* (December 1994), a comprehensive listing of the most widely used indicators for evaluating family planning programs in developing countries. The indicators are organized within a conceptual framework that specifies how programs are expected to achieve results at the program and population levels. Indicators are provided in the following categories: policy, environment, services delivery operations, services output, demand for children, demand for family planning, service utilizations, contraceptive practice, and fertility impact.

Other documents include *Working Group on the Evaluation of Family Planning Training: Final Report* (February 1994), a list of indicators to measure the effects of training on family planning service delivery; *Working Group on the Evaluation of Family Planning Policy: Final Report* (March 1995), a list of indicators to measure the effects of policy activities on family planning demand and service delivery; *Indicators for Reproductive Health Program Evaluation* (December 1995), a range of indicators that address healthy interventions for pregnant women and for newborns; and *Evaluating Information-Education-Communication (IEC) Programs for Family Planning and Reproductive Health* (October 1996), providing an inventory of indicators that can be used in evaluating different types of IEC interventions and prepared as an update to the IEC section of the *Handbook of Indicators for Family Planning Program Evaluation.*

Family Planning Councils of America (FCPA)
960 Penn Avenue, Suite 600
Pittsburgh, PA 15222
www.fpcai.org

The FPCA is supporting a project to develop, recommend, and test in service delivery settings, a core set of performance measures that can be used by the field to describe the effectiveness and impact of family planning services. The approach is to develop a core set of performance measures based on a systematic assessment of goals and strategies. The first stage of work, defining and recommending a core set of indicators, has recently begun and is expected to conclude in Spring 2000. The second stage will be a demonstration project to assess the feasibility of instituting a performance measurement system in selected family planning sites.

Family Health Council of Central Pennsylvania
3461 Market Street
Suite 200
Camp Hill, PA 17011

Two handouts list a combination of indicators for chlamydia and family planning programs. These indicators focus on process, outcome, or structure and describe an analysis plan. This plan describes the type of analysis, results of the analysis, what is looked for in the results, and action to be taken based on the results of the analysis.

HEDIS (Health Plan Employer Data and Information Set) 2000
National Committee for Quality Assurance
2000 L Street, NW
Washington, DC 20036
(202) 955-3500
http://www.ncqa.org

HEDIS is a set of standardized performance measures designed to ensure that purchasers and consumers have the information they need to reliably compare the performance of managed health care plans. The performance measures in HEDIS are related to many significant public health issues such as cancer, heart disease, smoking, asthma, and diabetes, among other public health issues. It also includes a standardized member satisfaction survey. Sponsored, supported, and maintained by the National Committee for Quality Assurance, the HEDIS is an ongoing assessment tool that is updated periodically by expert panel recommendations.

Healthy People
United States Department of Health and Human Services
Office of Disease Prevention and Health Promotion
Hubert H. Humphrey Building, Room 738G
200 Independence Avenue, SW
Washington, DC 20201
http://web.health.gov/healthypeople

Healthy People is a national prevention initiative used by the US Department of Health and Human Services for the past two decades to improve the health of the American people. The first set of national health targets was published in 1979 in *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention*, with five goals to reduce mortality among four different age groups—infants, children, adolescents, and young adults—and increase independence among older adults. Building upon the lessons of the first Surgeon General's report, the framework of *Healthy People 2000* consists of three broad goals—health promotion, health protection, and prevention services—with more than 300 national objectives organized into 22 priority areas. The Department is currently developing a new set of national objectives, *Healthy People 2010*, which were released in January 2000. As the process of developing new national goals and objectives for 2010 began, the Department of Health and Human Services also

saw an opportunity to build upon this foundation by establishing a small set of leading health indicators, which will be presented as an introduction to Healthy People.

Improving Health in the Community: A Role for Performance Monitoring
Institute of Medicine
J. S. Durch, L. Bailey, and M. A. Stoto, Editors
National Academy Press
2101 Constitution Avenue, NW
Washington, DC 20418
(800) 624-6242
http://www.nap.edu

In 1997, the Institute of Medicine completed a two-year study to examine the use of performance monitoring and develop sets of indicators that could be used by communities to promote the achievement of public health goals. The project was funded largely by the US Department of Health and Human Services and the Robert Wood Johnson Foundation, initially in response to the proposal for the Health Security Act of 1994, and later focused on how a performance monitoring system could be used to improve the public's health. The report recommends a community health improvement process, with emphasis on measurements to link performance and accountability for public health on a community-wide basis. It incorporates a variety of theoretical and practical models from health care, public health, and other settings, attempting to integrate these models into an overarching conceptual framework while illustrating its application thorough prototype indicator sets.

Key Indicators for Family Planning Projects
World Bank Technical Paper Number 297, September 1995
Rodolfo A. Bulatao, Editor
1818 H Street, NW
Washington DC 20433
http://www.worldbank.org

This paper lists numerous indicators that could be used to monitor and evaluate family planning and suggests 10 potentially useful indicators for most projects. These 10 indicators cover all aspects of a family planning program: program inputs, capacity, and process outputs; behavioral outcomes among clients; and long-term demographic outcomes. The paper also discusses the functions of indicators: tracking, monitoring, evaluation, comparison, and preparation. Criteria for selection are also discussed.

Maternal and Child Health Bureau
Title V Block Grant Program
Dr. Peter van Dyck, MD, MPH
Kerry Nesseler, RN
5600 Fishers Lane, Room 14-45
Rockville, MD 20857

National Center for Education in Maternal and Child Health
2000 15th Street, North, Suite 701
Arlington, VA 22201-2617
(703) 524-7802
http://www.ncmech.org

The Title V block grant guidance has been consolidated into a combined annual report and applications document with 18 national core performance measures, as well as state-negotiated performance measurements on which states report. The revised format offers a consistent way for states to provide tabular information, which can be aggregated to reflect the block grant effort. These measures are classified by the aspect of the maternal and child health services being addressed—capacity, process, risk factors—and by the level of core public health pyramid. Each measure is described in terms of six major components: goals, measure, definition, Healthy People objective, data source, and significance. In conjunction with the National Center for Education in Maternal and Child Health, the Maternal and Child Health Bureau has developed the Title V Information System for electronic storage and retrieval of information from the block grant applications and annual reports. In 1998, all states began using the Title V Information System's data collection tool, the Electronic Reporting Package (EDP). The EDP is an easy-to-use database application that allows states to complete required forms for their annual block grant applications and reports. The National Center for Education in Maternal and Child Health is currently developing a Title V Web site where users will be able to search, sort, and display Title V data in a variety of table formats. The Bureau is now developing another separate set of health status indicators to be included in the July 2000 Title V Block Grant Application and Annual Report. Three pilot states—New York, Rhode Island, and Texas—have tested the collection and utilization of the indicator data.

Perinatal and Women's Health Issues Summaries
Copies of the summaries can be requested by calling the National Maternal and Child Health Clearinghouse at 703/356-1964 or by visiting http://www.med.jhu.edu/wchpc/index.html.

Prepared by the Women's and Children's Health Policy Center at the Johns Hopkins School of Public Health and sponsored by the Maternal and Child Health Bureau,, this set of 13 issues summaries highlights policy and program areas in need of improvement in the field of perinatal and women's health. A two-volume compendium, *Charting a Course for the Future of Women's and Perinatal Health*, provides a more detailed overview of the background and findings on the specific topics. The summaries include statistical and qualitative data; address interventions as well as implications for policy, programs, and research; and provide references on the following: 1) The Social Context of Women's Health, 2) Women's Reproductive Health and Overall Well-Being, (3) Women's Experience of Chronic Disease, (4) Depression in Women, (5) Abuse Against Women by Their Intimate Partners, (6) The Nutritional Status and Needs of Women of Reproductive Age, (7) Women's Physical Activity in Leisure, Occupational, and Daily Living Activities, (8) Effects of Drug and Alcohol Use on Women's and Perinatal Health, (9) Effects of Smoking on Perinatal and Women's Health, (10) Pregnancy Planning and Unintended Pregnancy, (11) Issues in Pregnancy Care, (12) Health Care Services and Systems for Women of Reproductive Age, and (13) Public Health Roles Promoting the Health and Well-Being of Women.

A Report Card on Women's Health: Addressing Women's Health Status at the National and State Level

University of Pennsylvania Medical Center
8th Floor Blockley Hall
423 Guardian Drive
Philadelphia, PA 19104-6021
(215) 898-2712

The work of this report card will be carried out through a unique partnership of three groups that combine the long-standing legal resources and public policy experience of the National Women's Law Center, the national preeminence of the Lewin Group health policy consulting firm, and Focus on Women's Health Research at the University of Pennsylvania Medical Center, one of six national Centers of Excellence in Women's Health. The project goal is to develop and test a pioneering policy and advocacy tool in the form of a comprehensive report card on women's health that uses a broad definition of health, a unified framework for analysis, and consistent indicators to measure the status of and investment in women's health on a state-by-state and national level. The report card will present a comprehensive framework of women's health that extends beyond traditional measures of health status to include those indicators that, by affecting women's lives, also have an impact on health status. It will couple health status and resource/investment indicators. Additionally, the report card will identify issues that cut across class and racial/ethnic differences, making possible a baseline of comparison for women's health between states and between the United States and other nations.

Selecting Indicators for Monitoring Reproductive Health

UNDP/UNFPA/WHO/World Bank Special Programme of Research and Development Training in Human Reproduction
PROGRESS in Human Reproduction Research, No. 45, 1998
World Health Organization
1211 Geneva 27 Switzerland

This issue of the PROGRESS quarterly newsletter looks specifically at the subject of reproductive health indicators. In its role as the lead agency for the Working Group on Reproductive Health of the United Nations Task Force responsible for the follow-up to the International Conference on Population and Development in 1996 and 1997, the World Health Organization convened two interagency meetings on reproductive health indicators for global monitoring. The article includes a minimal list of 15 reproductive health indicators recommended by the meeting participants and explains what health indicators are, how they are expressed, and what they are used for. It also includes an explanation of criteria to use in selecting indicators, as well as a number of "key issues" that should be borne in mind by anyone using indicators.

Standards of Care

Regional Program Advisory Committee (RPAC)
Region VI

This project aims to improve understanding and implementation of standards of practice or benchmarks currently utilized for family planning within the universal health care system, including some "managed care" relevant indicators. The overall goal is to improve the delivery of family planning services. The project identified commonly utilized measures or indicators of family planning health care in a variety of domains, including service delivery, administration, outreach, prevention, and others. The project is ongoing and one of the expected results is an analysis of how these elements compare in the public and private arenas.

The Status of Women in the United States: Politics-Economics-Health-Demographics
Institute For Women's Policy Research (IWPR)
1400 20th Street, NW
Suite 104
Washington, DC 20036
http://www.iwpr.org

This series of reports compiles crucial data about the issues affecting women to provide policy makers with reliable and relevant data about women in order to achieve gender equality. The choice of key indicators was largely guided by the Beijing Declaration and Platform for Action from the United Nations' Fourth World Conference on Women. Composites represent indices (which allow ranking and comparisons among states) on political participation and representation, employment and earnings, economic autonomy, and reproductive rights. Health and Vital Statistics and Basic Demographics are also included.

Women of Color Data Book: Adolescents to Seniors
National Institutes of Health
Office of the Director
Office of Women's Health
NIH Publication No. 98-4247

The data book focuses on a totality of factors believed to contribute to health and specifically on three sections: factors affecting the health of women of color (ethnicity and race, subpopulations, demographics, access to services, health risk and healthful behaviors) and health assessment of women of color (major causes of death, behavior and lifestyles, preventive health care services, access to health insurance and services, morbidity and mortality), and issues related to improving the health of women of color.

Women's Health Data Book: A Profile of Women's Health in the United States
State Profiles on Women's Health
Jacobs Institute of Women's Health
Jacqueline A. Horton, ScD, Editor
409 12th Street, SW
Washington, DC 20023-2188

These two 1998 publications focus in detail on national data that describe the health status and major causes of morbidity and mortality for women in the United States and then describes this at a state level. These publications include basic demographic information, major risk factors for illness, leading causes of death and disease, health insurance coverage, preventive health services, and policy issues. Comparisons and trends can be observed.

APPENDIX B:

COMPREHENSIVE FAMILY PLANNING SERVICES AND RELATED REPRODUCTIVE HEALTH SERVICES

During the Phoenix meeting, the Title X Applicability workgroup developed the following list of services that fit under the concepts of *comprehensive family planning services* (as represented by the scope of services implied by Title X) and *related reproductive health services*. This list address aspects of clinical care and counseling only. The workgroup had insufficient time to examine the potential range of activities surrounding the other Title X mandates, such as community education, training, or research. This list should not be considered complete, as it requires refinement and input from a wider range of Title X service providers and from the staff of the Office of Population Affairs and the Department of Health and Human Services. It should, however, provide insight into the kinds of program performance indicators that might be derived from this framework.

1. Comprehensive Family Planning Services (provided to females and males):
(Core and Expanded Title X Program Indicators would come from this list.)

Clinical:

- All contraceptive methods and services(including sterilization, emergency contraception, and natural family planning)
- Pregnancy testing and uterine sizing
- Post-pregnancy contraceptive care
- Screening for sexually transmitted diseases (STDs), including gonorrhea, syphilis, chlamydia, and HIV
- Care for treatable STDs (either on site or through documented referral and follow-up)
- Partner services for STDs (preferably on site or, alternatively, through documented referral)
- Health screening for blood pressure, anemia, nutrition, weight, smoking, substance use
- Screening for sexual functioning (sexual history)
- Screening for domestic violence, coercion
- Reproductive cancer screening (including cervical, breast, prostate, and testicular cancers)
- Screening and referral for genetic conditions affecting healthy pregnancies
- Referral and follow-up for abnormalities uncovered in screening assessments

Counseling and education to:

- Provide nondirective counseling on pregnancy options (prenatal, adoption, and abortion)
- Improve effective use of contraception
- Reduce reproductive health risks
- Improve preconception health status
- Address fertility and infertility concerns
- Address concerns of adolescents: coercion, abstinence, and parental involvement

- Address personal responsibility in relationships
- Instruct individuals on breast and testicular self-examination

2. Related Reproductive Health Services (provided to females and males):
(Expanded indicators may come from this list, as appropriate to Title X legislation.)

Clinical:

- Treatment for abnormal clinical findings (such as amenorrhea, anemia, etc.)
- Infertility diagnosis and treatment
- Reproductive cancer diagnoses and treatments (colposcopy, mammography, etc.)
- Prenatal and perinatal care
- Delivery
- Breast-feeding and lactation
- Sexual functioning
- Immediate postpartum care
- Management of peri- and postmenopause
- Reproductive health care for sterilized individuals (Pap smears, prostate screening, etc.)
- Abortion services*
- Diagnosis of genetic conditions affecting a healthy pregnancy

Counseling services to:

- Ameliorate or provide therapeutic interventions for domestic violence or coercion
- Assist couples with infertility and adoption issues
- Address hereditary genetic disorders
- Improve sexual response and functioning

* Although induced abortion is a legal procedure and a service component of reproductive health care, it is prohibited by legislation from being offered within the Title X Family Planning Program.

APPENDIX C:

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GLOSSARY

Behavioral Risk Factor Surveillance System (BRFSS): An ongoing data collection telephone survey of the U.S. civilian, noninstitutionalized, adult population. The BRFSS is administered and supported by the Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention. It collects state-specific information to determine the prevalence of high-risk behaviors such as cigarette smoking, physical inactivity, and drinking and driving, as well as preventive practices. www.cdc.gov/nccdphp/brfss

Belmont Report: The result of a 1976 conference held by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, this report summarizes the basic ethical principles and guidelines for the protection of human subjects of research. www.med.umich.edu/ethics/belmont/BELMONTR.HTM

Consistency: For the purposes of this document, *consistency* refers to a condition of agreement or compatibility in which things conform to the same principles or course of action and are uniform.

Core indicators: A representative set or subset of indicators reflecting key concepts.

Family Planning Annual Report (FPAR): A report providing annual service data, which all grantees receiving funding under the federal Title X program are required to submit.

Government Performance and Results Act (GPRA): Legislation enacted by the U.S. Congress in 1993, which seeks to shift the focus of government decision-making and accountability to a focus on the results of activities, such as real gains or program quality. Under the Act, agencies are to develop multiyear strategic plans, annual performance plans, and annual performance reports.

Health outcome measures: An indicator of the results or consequences of a process of care. Health outcomes may include satisfaction with care as well as the use of health care resources. Included are clinical outcomes, such as a change in health status and changes in the length and quality of life as a result of the detection or treatment of disease.

Health Plan Employer Data and Information Set (HEDIS): A set of standardized performance measures that are sponsored, supported, and maintained by the National Committee for Quality Assurance (NCQA). HEDIS is designed to ensure that purchasers and consumers have the information they need to reliably compare the performance of managed health care plans. HEDIS performance measures are related to many significant public health issues, such as cancer, heart disease, smoking, asthma, and diabetes. HEDIS also includes a standardized survey of consumers' experiences that evaluates plan performance in areas such as customer service, access to care, and claims possessing.

Heath status measures: Measures that represent a broad overview of a community's health and that can be used by various levels of government.

Healthy People 2010: A national prevention initiative, administered by the Department of Health and Human Services, that identifies opportunities to improve the health of all Americans through the use of health promotion and disease prevention objectives. www.health.gov/healthypeople

Indicator: A statistical tool used to summarize data that have been collected in order to answer questions about the planning and management of health programs. Health indicators are used to assess a population's health status, to monitor the implementation and outputs of a program, and to evaluate the effectiveness and impact of a program. Health indicators are expressed in terms of absolute numbers, rates, proportions, averages, or categorical variables.

Input measures: A statistical measure showing the amount of resources that are being used for a particular planned activity over a specific period of time.

International Conference on Population and Development (ICPD): A meeting of the United Nations World Health Organization held in Cairo in 1994 that discussed issues of reproductive health, population growth, and economic development. www.undp.org/popin/icpd

National Committee for Quality Assurance (NCQA): An independent, non-profit organization whose mission is to evaluate and report on the quality of the nation's managed care organizations. NCQA sponsors and supports the HEDIS set of performance measures. www.ncqa.org

National Survey of Family Growth (NSFG): A survey conducted by the National Center for Health Statistics that provides current information on pregnancy, childbearing, contraception, and related aspects of maternal and child health. There have been five rounds of data collection, each based on a nationally representative sample of women aged 15-44, interviewed in person in their own households. www.cdc.gov/nchs/nsfg.htm

Needs assessment: A formal process of identifying problems and assessing a community's capacity to address health and social service needs. It is often the first step in a community health improvement process.

Output measures: A statistical measure showing a product or accomplishment in measurable terms of the activities of an individual over a specific period of time.

Performance measure: A statistical measure that signifies the extent to which a program is meeting its long-term objectives.

Pregnancy Risk Assessment Monitoring System (PRAMS): PRAMS is a surveillance project administered by the Centers for Disease Control and Prevention (CDC) and state health departments. PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and immediately after pregnancy. www.cdc.gov/nccdphp/drh/srv_prams.htm

Process measure: A statistical measure showing the activities that will be completed in order to achieve a specific objective over a specific period of time.

Proxy: A variable used to stand in for one that is difficult to measure directly.

Reliability: The extent to which scores obtained on a measure are reproducible in repeated administrations, provided that all relevant measurement conditions are the same.

Sensitivity: A measure of the validity of a test, defined as the ability of an indicator to correctly indicate a positive result if the condition, disease, or state is actually present.

Specificity: A measure of the validity of a test, defined as the ability of an indicator to correctly indicate a negative result if the condition, disease, or state is actually not present.

Title X: A program administered by the Office of Family Planning of the Office of Population Affairs, U.S. Department of Health and human Services. The Title X program supports grants to provide comprehensive family planning and reproductive health services to all persons who want them. These services include contraceptive services and supplies, basic gynecologic care, cancer and general medical screening, infertility services, education, counseling, and referral. www.hhs.gov/progorg/opa/titlex/ofp.html

Validity: The extent to which a measure reflects the concept it is intended to measure.

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